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Cochlear implants in the deaf community: Current circumstances of cochlear implant users among the deaf youth in Sweden's educational system

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Cochlear Implants in the Deaf Community:
Current Circumstances of Cochlear Implant Users among the Deaf Youth in Sweden's Educational System

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Abstract

Sweden has maintained an environment of equal opportunities and inclusive disability policies for its citizens. In Swedish education, a bilingualism method of Swedish Sign Language and spoken Swedish is used in teaching deaf children. The cochlear implant device is considered an advanced form of hearing technology and is used with deaf youth to assist with speech development. Several medical experts and researchers support the language development theory that there is a "critical period" for a deaf person to acquire natural language and speech development at a young age. Some experts believe that in order to achieve this language acquisition of the spoken language, deaf children are encouraged to get implants as early as possible.

The focus of this thesis is to examine how the emergence of cochlear implant technology impacts Sweden's environment toward existing disability policies and procedures in education, health care, and organizations serving deaf people. This thesis will be addressed in the following 3 ways:

1) Provide current documentation of criteria and processes for obtaining a cochlear implant.

2) Gather existing policy statements on cochlear implants from major organizations serving deaf people.

3) Collect historical and current statistical data of the deaf population who have cochlear implants or hearing aids in compulsory education including special schools (first grade to ninth grades).

To explore the current circumstances of cochlear implant use in the educational environment in Sweden, an in-depth literature review was conducted about Sweden's history and background of cochlear implant use. Surveys were distributed to five major community organizations and agencies serving deaf people as well as six community hospitals about the process and procedures for obtaining cochlear implants in Sweden. This research process collected information that occurred predominantly mostly in 2007 followed by interpretations, analysis of the survey results, and new findings.

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List of Acronyms

Acronym	in English	in Swedish
SDR	The Swedish National Association of the Deaf	Sveriges Dövas Riksförbund (SDR)
DHB	The Swedish National Association for Deaf, Hearing-Impaired and Language-Impaired children	Riksförbundet för döva, hörselskadade och språkstörda barn (DHB)
Euro-CIU	European Association of Cochlear Implant Users	n/a
SCB	Statistics Sweden	Statistiska centralbyrån
DO	Equality Ombudsman	Diskriminneringsombudsmannen (DO)
SI	Swedish Institute	Svenska institutet
OSS	The National Agency for Special Needs Education and Schools	Specialpedagogiska skolmyndigheten

1.0 Introduction

Cochlear implant technology, one of the most advanced technical devices for people with significant permanent hearing loss, has been studied around the world. Sweden is one of many countries to take advantage of this technology. It is wondered how the emergence of cochlear implant technology impacts Sweden's environment toward existing disability policies and procedures in education, health care, and organizations serving deaf people. This research question will be addressed in the following three ways:

1) *Provide current documentation of criteria and processes for obtaining a cochlear implant.* Are the criteria and process for receiving cochlear implants in Sweden any different from the United States? How does the medical team support the bilingualism policy through various types of hearing assistive devices? There are six hospitals in Sweden that perform cochlear implant surgery and a questionnaire was sent to each to collect information on its cochlear implant criteria and the process that a patient undergoes for receiving cochlear implants.

2) *Gather existing policy statements on cochlear implants from major organizations serving deaf people.* Do some major organizations support cochlear implant technology? Does the policy statement from each major organization support bilingualism policy in Sweden? Five different groups were identified to have worked with the deaf community and were given a questionnaire about its perspectives toward cochlear implants.

3) *Collect historical and current statistical data of the deaf population who have cochlear implants or hearing aids in compulsory education including special*

schools (first grade to ninth grades). Are there any statistics on the number of deaf people wearing hearing aids or cochlear implants? How many deaf children with cochlear implants are integrated into regular schools and special schools? Data were found in reports, publications, and through several agencies that collect statistics.

The emergence of cochlear implant technology influences the way society views deafness and its policies. Notably, cochlear implant technology has significant influences on the perspectives from experts in the medical field and from the deaf community. People in the deaf community share common experiences and in many places use sign language as their main form of communication. Many medical experts would like to help a deaf person hear as much as possible by recommending the most advanced technology available, which currently is the cochlear implant.

There are people within the deaf community who believe, regardless of the various medical solutions for a person with hearing loss, that there is a natural yearning for deaf culture, deaf identity, and sign language. For some people, hearing assistive devices such as cochlear implants, middle ear implants, and hearing aids are just a medical fix to the hearing loss, but it does not completely bring the person to a normal hearing level. Deaf individuals each have their own perspectives toward new technology. Some may fear new technology and resist it because it threatens the value of deaf culture and the use of sign language whereas some may embrace it because it connects the deaf community with those who can hear. Technology influences the way deaf individuals define their own identity such as proudly being a Deaf person, a hard of hearing person, or belonging to neither group.

A cochlear implant is a device that replaces the function of hair cells incapable of producing electrical impulses to the auditory part of the brain as sounds travel through the ear. Cochlear implants do not restore normal hearing. Instead, the technology gives a deaf person greater access to sound. Individual benefits range from the ability to hear environmental sounds to understanding speech in most situations. (National Institute on Deafness and Other Communication Disorders [NIDCD], 2009). "According to the Food and Drug Administration (FDA), as of April 2009, approximately 188,000 people worldwide have received implants. In the United States, roughly 41,500 adults and 25,500 children have received them" (NIDCD, 2009).

Research studies have been conducted on the use of advanced technology in early intervention for hearing loss, and the use of cochlear implants is growing worldwide to support the development of spoken language. Intervention can begin shortly after birth. At Swedish hospitals, a Universal Neonatal Hearing Screening test is given to all newborns to identify hearing loss. Parents with their deaf child are referred to a medical team and educated on deafness. The health care system is funded through taxes by the government to provide people in Sweden free health and medical care. Cochlear implants and medical services are provided to deaf people as part of this health care system. Currently, Swedish hospitals have no government regulations on cochlear implants and some follow the criteria suggested by the manufacturers.

Several research studies support the theory of "critical period" where the child at early stages of development acquires and masters the spoken language. This theory is directly linked to the belief that the child with a hearing loss must be able to hear as early as possible through using technical devices such as hearing aids or cochlear implants.

Cochlear implants are considered to be the advanced form of hearing assistive devices that allow a child to perceive environmental sounds more clearly than hearing aids, which mostly amplify the sounds. As stated earlier, the use of cochlear implants does not restore hearing immediately, it requires training to learn and understand the sounds. Having a cochlear implant early helps a deaf child develop speech (spoken language skills) (NIDCD, 2009).

Many countries view Sweden as a leading model in the studies of cochlear implant technology. Although there are no regulations on the use of cochlear implants in Sweden, people worldwide study the Swedish model to create new policies for their home country to support or regulate cochlear implants.

The bilingualism policy encourages the use of technology to help deaf people with development of spoken language. However, in 1981, the Swedish government also officially recognized Swedish Sign Language as a primary language before spoken Swedish for the deaf community. The new policy allowed the deaf community to embrace Swedish Sign Language and protect their rights to communicate in their own language.

Furthermore, a literature review will describe the background of Sweden's government, organizations, education, accommodations for the deaf, health care system, and the process for receiving cochlear implants. This thesis will also discuss the distribution of questionnaires and the findings from organizations, agencies, and hospitals about the procedures for receiving a cochlear implant, statistical data for the number of cochlear implants and hearing aids users in Sweden, and any policy statements from organizations and agencies on cochlear implants. This is followed by implications for the

United States based on Sweden's experience and recommendations for future studies on cochlear implants use.

2.0 Literature Review

2.1 Sweden's background

Located north of Europe in the Scandinavian region is a country where approximately 9,336,487 people call Sweden their 'People's Home' (Statistics Sweden, November 2009). The native language is Swedish; however, minority native languages such as Sami, Finnish, and Swedish Sign Language are used. Most children are taught English as a second language in elementary school so that they can participate in the global community. Sweden is one of the leading models for bilingualism and multicultural integration (Swedish Travel & Tourism Council, 2003). This is because immigrants comprised approximately 10 percent of the total population in 2002. Furthermore, the relaxed immigration policy in the 1960s increased innovations in education, technologies, health care, and the global market (Odom & Kaul, 2003).

Research and development play very important roles as investments in Sweden's future. Its ambitions and industrial speed in adopting new technology is internationally recognized. Thus, major multinational corporations have used Sweden as a test market for development of new products and services including cochlear implants (Swedish Institute, May 2009).

As an egalitarian society, many of the ideas were borrowed from socialism in which the government prioritizes people's safety and security to maintain one of the best living standards in Europe or perhaps the world. Sweden maintains its society by practicing democratic values in schools and foreign affairs while it continues to be

modern and industrial. People put faith in their government to enable a safety net that minimizes their fear of potential costs of unemployment, medical difficulties, or education (Stratton, 2007). This includes creating disability policies making their society accessible for all.

The Swedish government structure is a multi-party system with different levels of governments such as national (state), county councils (regional), and municipalities (local). There are twelve different ministries that formulate government regulations and laws for the Riksdag (Parliament) to discuss and to enforce policies especially for those with disabilities (Swedish Institute, 2008). The Equality Ombudsman oversees and helps to create the disability policies (Diskriminerings Ombudsmannen, 2008a). Health and dental care, free to all children and youth, are provided through the responsibilities of the Ministry of Health and Social Affairs (Regeringskansliet: Government Offices of Sweden, 2009). Children have been receiving free health and medical services since 1937 (Odom & Kaul, 2003). The Swedish government provides services such as education, health and medical care, pensions, social services, and economic securities to the citizens at no additional cost other than from taxes (Odom & Kaul, 2003; Invest in Sweden Agency, 2009). This includes providing hearing assistive technologies for the deaf.

The extended literature review will cover existing disability policies and the emergence of cochlear implant technology in education, health care, and organizations serving deaf people.

2.2 The Swedish government, laws, and disability policies

An ideal community is one in which everyone is able to participate equally and vote on issues without any form of discrimination. In Sweden, policy makers must keep in mind their disabled citizens when creating or revising laws. Therefore almost each act or provision has some sort of clause in regards to people with disabilities (Swedish Institute, 2007). For example, *The Health and Medical Service Act* mandates that county councils be responsible to finance community interpreters. *The Education Act* allows special schools to exist for deaf children to receive additional support that a regular school may not be able to provide. There are no Acts in Sweden similar to the Americans with Disabilities Act (ADA) created in the United States. Instead, some Swedish Acts or legislations have specific clauses to support people with disabilities.

The deaf community in Sweden has made great strides in protecting their language and culture. As mentioned earlier, the Swedish Parliament recognized Swedish Sign Language in 1981 as one of the official languages in Sweden and the primary language of the deaf community (DeCaro, Mudgett-DeCaro, & Dowaliby, 2001; Preisler, Tvingstedt, & Ahlström, 2002). Many policies support the use of Swedish Sign Language such as subsidizing costs for sign language training for parents through the TUFF program (Sveriges Dövas Riksförbund, 2007a).

The Health and Medical Service Act of 1982 (1982:763) provides an essential need for Swedish residents. The goal of this Act is to provide equal access to good health care. The cost of health and medical care amounts to SEK 223 billion (approximately $30.9 billion) or 8.4% of Sweden's GDP. The state is responsible for nationwide policies and medical care programs. For the Swedish deaf, the county councils work with the

residents in their region toward services that require considerable resources such as interpreting services. The 21 county councils offer their residents services such as habilitation and rehabilitation, assistive devices for persons with functional impairment, and interpreting services (Regeringskansliet: Government Offices of Sweden, 2004). If a deaf person wants a cochlear implant, he/she would receive support through the county council.

All children and young persons have equal access to education in the national school system from pre-schools to compulsory secondary schools, Sami schools for the native Scandinavians, and special schools for children with special needs. This is supported through the Education Act (1985:1100). The special schools are for children who need additional assistance that is not provided by the national school system. These children will receive the same education curriculum that is taught in regular schools. The only difference between the national school system and the special schools is that special schools have teachers and personal assistants that are trained to work with children of various disabilities. Deaf students are required to have an additional year of sign language to their curriculum.

Education is free for children with disabilities, and the state is responsible for expenses such as books, meals, writing materials, transportation, and housing for students who live long distances from home (listed in Chapter 7 of the Education Act). Children with functional impairments may choose to go to any school. In addition, they are given the choice to attend special schools. For regular schools, they have a specialized department linked to assist those students with special needs (The European Social Network, 2000). In Sweden, there are independent schools or private education that

accepts students with special needs with their own budget and grants. Parents who want to send their child with disabilities to an independent school can receive grants covering up to 85% of tuition paid for by the government, according to the Freedom of Choice and Independent Schools Bill of 1992 (Andrew, 2002; Merrifield, 2005). The National Agency for Education monitors all education issues, and the local authorities are responsible to provide educational support to students in their region (The European Social Network, 2000).

The establishment of the Disability Ombudsman Act in 1994 was to monitor issues regarding the rights and interest of people with disabilities and to make sure that they have equal access and fair treatment without comprising their individual integrity. The Disability Ombudsman has the authority to mandate that county councils and municipalities report and perform functions relating to people with disabilities. The Disability Ombudsman provides information about community activities and funds. All levels of government must report to the Disability Ombudsman any activities regarding people with disabilities. Evaluation of their policies and procedures is required to make sure that there are no discrimination activities and that the regulations are fair. The Disability Ombudsman was one of the few offices that merged under the Equality Ombudsman (Handikappombudsmannen, 1994; Vocational Rehabilitation and Employment of Persons with Disabilities, 2007b; Diskriminerings Ombudsmannen, 2008a).

There are advocacy organizations that express their concerns to national authorities for people with disabilities. One example of an advocacy organization is the Swedish Disability Federation, which was founded in 1942 and consists of over 37

national disability organizations and about 450,000 members. The Swedish Disability Federation is part of the Advisory Council under the Equality Ombudsman and reports on specific disability issues (Vocational Rehabilitation and Employment of Persons with Disabilities, 2007a).

Most of these policies and organizations made sure that all citizens, especially those with disabilities, have access to education, medical and health services, social participation, and working environments. The politicians behind these policy-making processes are trained to ensure that when creating new Acts, they will be all-inclusive. If missing any, they will create a provision to include equality. Finally, the policies will be accessible for disabled citizens. Some of the other acts regarding people with disabilities can be found in Appendix G: Swedish policies dealing with people with disabilities.

2.3 Advocacy organizations, government agencies, and international affiliations

This section of the thesis will focus on five major organizations and agencies that advocate for deaf citizens in Sweden in addition to several affiliations. The names are in Swedish and a translation will be given. A brief insight into the organization's history, membership and purpose will be shared. Sweden has international affiliations through some organizations.

Major organizations, agencies, and affiliations at the international level:

1) SDR-
   Sveriges Dövas Riksförbund, *the Swedish National Association of the Deaf.*

2) Barnplantorna-
   Barnplantorna, roughly translated to "Children Implant," is known as *the National Association for Children with cochlear implants in Sweden*.

3) DHB-
   Riksförbundet för döva, hörselskadade och språkstörda barn or "DHB" is translated into *the National Association for the deaf, hearing impaired and language impaired children*.

4) Skolverket-
   Skolverket, *the Swedish National Agency for Education.*

5) Equality Ombudsman-
   Handikappombudsmannen or HO was the former *Disability Ombudsman* before it merged with three other ombudsman offices under a new name as Diskriminerings Ombudsmannen, *Equality Ombudsman* or DO. The objectives of the former Disability Ombudsman did not change after they merged the four offices into the new Equality Ombudsman.

6) European Association of Cochlear Implant Users (Euro-CIU)

7) The Nordic Council of the Deaf

8) The World Federation of the Deaf (WFD)

9) European Union of the Deaf

The Swedish National Association for the Deaf (SDR)

The first Association of the Deaf in Sweden was established in 1868 in Stockholm as a national club serving deaf people all over the country and offering funds toward health insurance and funeral expenses. By the end of the 1890s, there were protests among the deaf community that they did not receive support because most funds were given only to the deaf people residing in Stockholm. As a result, several deaf clubs formed independently around the country to support their local deaf needs. In 1919, the Gothenburg Deaf Club brought fourteen different club representatives together and discussed a need for a central organization in Sweden. On February 26, 1922, the Swedish National Association of the Deaf was formed to work with all the deaf clubs in sharing similar interests on the national level (Sveriges Dövas Riksförbund, 2010b).

SDR works with politicians and community organizations to ensure full access to media, education, employment, health and public services for deaf people (Sveriges Dövas Riksförbund, 2010d). SDR serves its members and the greater community by advocating for the deaf community for the right to communicate and receive information in Swedish Sign Language. SDR also works with various groups of people such as parents of deaf children, deaf senior citizens, interpreters, teachers of the deaf, and many others by providing information and resources. In the 1980s, the deaf community wanted to strengthen the communication between the teachers and the students by implementing two policy changes. These two policy changes were aimed at improving the skills of teachers for the deaf: "1) Entrance requirements must were changed so that individuals entering the training program to become teachers of the deaf must first pass a rather stringent sign language test. 2) A five-year federal grant was given to Stockholm University to set up a one-semester sign language program for individuals who are already teachers" (Davies, 1991). In addition to the recognition of sign language in 1980/81, the Swedish Parliament decided to promote bilingualism as part of the deaf society in Sweden (Davies, 1991). Today, SDR is actively involved with the World Federation of the Deaf, Nordic Council of the Deaf, and European Union of the Deaf at the international level (Sveriges Dövas Riksförbund, 2010c).

SDR is an advocate for the use of sign language in Sweden regardless of deaf people who use cochlear implants or not. Users of sign language, whether the person is hearing or deaf, can apply for membership within the SDR. Several community opinions assume that SDR is against cochlear implants. Thus, SDR responded back with a

statement on its website, “During the year we formulated our view of cochlear implants in a statement. We wanted once and for all to make clear that SDR is not against the CI, but for sign language” (Sveriges Dövas Riksförbund, 2007b, p. 5). SDR also believes that all deaf children should be given the privilege to learn both spoken Swedish and Swedish Sign Language regardless of what hearing assistive technology they use. With or without the hearing assistive technology, the people who use it are still deaf. SDR wants to make sure that these children have access to the society in their natural language, which is sign language (Sveriges Dövas Riksförbund, 2007b).

Several statistics on the size of the deaf population in Sweden are scattered throughout the SDR’s website. In 2010, there were about 4,500 members with forty clubs at the local and county level (Sveriges Dövas Riksförbund, 2010e).

Barnplantorna

Barnplantorna is a support organization and resource for parents who have children with cochlear implants. It was founded in 1995 through four families in Gothenburg that needed an association to support their children and their use of cochlear implants. In 2007, Barnplantorna included children with middle ear implants and hearing aids as part of the organization. The middle ear implant is a sound processor for the middle ear that is placed behind the ear but directly into the bone to conduct the sounds toward the functioning cochlea (Cochlear Americas, 2009). Barnplantorna influences the government and society on technical development for CI, middle ear implant, and hearing aids. The organization also provides information to schools on how to incorporate children using hearing assistive devices into the classroom (Barnplantorna, 2009a).

Barnplantorna gives advice to parents on how to receive financial support from the government for their child with hearing assistive devices. The compensation from the government can range from 2229 SEK to 8917 SEK (approximately $295 to $1,175) per month with the proper insurance and paperwork (Barnplantorna, 2010a). About 40,000 parents receive support from the government; however, there are other parents who are unaware of this government funding. Furthermore, Barnplantorna emphasizes the importance of spoken language and communication training for parents of deaf children. On its website, it mentions briefly the deaf community and the use of Swedish Sign Language as part of deaf culture (Barnplantorna, 2009c).

Barnplantorna worked hard in making the Universal Neonatal Hearing Screening a national requirement in all hospitals in Sweden. According to Barnplantorna, there are about 10,000 hearing impaired and deaf children up to 20 years of age in Sweden (Barnplantorna, 2009b). Generally, 200 children are born each year with some kind of hearing loss (Barnplantorna, 2008b, p. 11). Each year, 20 deaf newborns are eligible for CI along with an additional 10 children who lost their hearing to an illness (Barnplantorna, 2009d).

Barnplantorna works with five regional hospitals that perform CI-surgery for children and adults by sending trained specialists on a CI-team to Uppsala Hospital, Karolinska University Hospital, University Hospital in Linköping, Sahlgrenska University Hospital, or Lund University Hospital (Barnplantorna, 2008b).

The Swedish National Association for the Deaf, Hearing-Impaired and Language-Impaired children (DHB)

Parents of deaf children are scattered throughout Sweden. Parents in the 1940s were in need of a national organization that would help educate parents of deaf children on how to participate in their community by creating a quality education and equal participation for their deaf children. In 1945, the Manila School, a special school for the deaf in Stockholm, formed the first parents' association. The parents at that time felt that the schools were lacking quality education for their deaf children and wanted to expand early education in nursery schools for deaf children (Riksförbundet DHB, 2009a). For years, parents and members of DHB have worked tirelessly to improve school conditions and quality of teachers.

DHB has a central office in Orebro and has committees responsible for five different regions community activities and parental support. DHB has been aggressive in pursuing quality education for children with hearing loss. In 1980, they participated in the change of curriculum to include sign language and have the textbooks and writing in simple forms to meet the deaf needs (Riksförbundet DHB, 2009b). DHB helped the government develop a statutory right of 240 hours of sign language instructions for parents of deaf children. DHB would like to expand this by increasing hours and including parents with children that have language disorders (Riksförbundet DHB, 2009c). Also, DHB works with politicians and authorities to provide better schools, sign language training and parenting for deaf children (Riksförbundet DHB, 2009d).

DHB acknowledges that spoken Swedish and Swedish Sign Language are two different communication methods with different grammatical structures. DHB believes

that Swedish Sign language should be the primary language for deaf children. Regardless of the type of hearing devices the children use, especially cochlear implants, it is believed that all deaf children have the need for sign language and it is a safe communication method in all situations (Riksförbundet DHB, 2009d).

One of the functions of DHB is to provide opportunities for members to get in touch with families with similar experiences. Members also receive information through the organization's magazine, which comes out four times a year about projects, conferences, camps and affiliations (Riksförbundet DHB, 2009d).

Skolverket (Swedish National Agency for Education)

Skolverket (Swedish National Agency for Education) is the central administrative authority for the public school systems in Sweden. The government and parliament defined the role of Skolverket through the Education Act of 1985. The major goal of this agency is to follow up with and evaluate the quality of education in public schools to make sure that all pupils have equal access. Skolverket covers all municipalities from preschool to college including vocational training schools (Skolverket, 2009b).

Municipalities have the responsibility to distribute resources and organize education so that students can achieve their national goals (Skolverket, 2009a). The national curriculum and the Education Act of 1985 define the school systems, basic goals and guidelines.

Compulsory education in Sweden is free and mandatory for children aged 7 to 16. The special schools for the deaf are free and have an extra year added to their curriculum to incorporate both spoken Swedish and Swedish Sign Language. For regular schools,

compulsory education is 9 years while for special schools it is 10 years. Skolverket oversees 8,062 schools in Sweden. In 2009, there were eight special schools for deaf students out of 4,949 compulsory education schools. The eight schools are: Birgittaskolan (Orebro), Ekeskolan (Orebro), Hallsboskolan (Stockholm), Kristinaskolan (Vasternorrlands), Manillaskolan (Stockholm), Vanerskolan (Vastra Gotalands), Asbackaskolan (Sodermanlands), and Ostervangsskolan (Skane). More information on these schools and their curriculum will be discussed in section 2.4. Deaf students have the option to attend either regular school or one of eight special schools. The municipality is responsible to make sure that accommodations are available for students attending regular schools (Skolverket, 2009b).

The Equality Ombudsman

The Discrimination Act was created to "combat discrimination and in other ways promote equal rights and opportunities regardless of sex, transgender identity or expression, ethnicity, religion or other belief, disability, sexual orientation or age" (Diskriminerings Ombudsmannen, 2008b). The Equality Ombudsman investigates complaints from citizens and makes sure that employers, schools, and the general community comply with the Act and the International Human Rights Declaration. The Equality Ombudsman received an allocation of 93 million SEK (approximately $13.2 million) in 2009 with 90 employees to monitor community activities and enforce the Discrimination Act (Diskriminerings Ombudsmannen, 2010). To the researcher's best knowledge, there is no policy statement about the use of cochlear implants. In the government bill (2008/09:153), *Language for All*, it protects the use of Swedish Sign

Language in the deaf community and complaints can be sent to the Equality Ombudsman for investigation.

European Association of Cochlear Implant Users (Euro-CIU)

Founded in 1995, The Euro-CIU is a collective member of European countries to represent the interest of deaf people who use or support the use of cochlear implant devices on the European level. They host bi-annual international symposia to disseminate information and promote awareness of cochlear implants and related research. Sweden has two memberships within the Euro-CIU: Västplantorna and Barnplantorna. Västplantorna focuses on the acceptance of cochlear implants at the national level in Sweden. Whereas, Barnplantorna focuses on cochlear implant issues for children (European Association of Cochlear Implant Users, 2008). On the website of Euro-CIU, it does not discuss the use or benefits of sign language in its mission. However its member, Barnplantorna, joined Euro-CIU to "distribute information about cochlear implants in children in order to make professionals (teacher, speech therapist, etc.) understand that children with cochlear implants can hear and develop spoken language as well as sign language" (European Association of Cochlear Implants Users, 2010).

The Nordic Council of the Deaf

Founded in 1907, the Nordic Council of the Deaf (DNR) consists of deaf associations from Denmark, Finland, Norway and Sweden. The Nordic Council of the Deaf meets twice a year with two representatives from each country: the President of each national association and one board member. Sveriges Dövas Riksförbund (SDR)

represents Sweden on this council. The purpose of this council is to promote sign language as an official language of the deaf people, exchange information and develop issues regarding the deaf in their country (The Nordic Council of the Deaf, 2005). The emphasis was on sign language alone, there was no mention of hearing assistive technologies such as cochlear implants on its website.

The World Federation of the Deaf (WFD)

Founded in 1951, the World Federation of the Deaf (WFD) is an international, non-governmental central organization of the National Associations of Deaf. Over 130 countries have membership within this organization. Like the United Nations, WFD works and supports human rights with a focus on Deaf people who use sign language as well as work toward a common goal against discrimination of people with various types and levels of hearing loss. Every four years, delegates meet at the General Assembly to discuss the status of national sign language, better education for deaf people, improving access to information and services, improving human rights for Deaf people in developing countries, and establishing deaf organizations in countries where none exist (World Federation of the Deaf, 2010). There is no policy statement about the use of hearing assistive devices on its website.

European Union of the Deaf

Founded in 1985, European Union of the Deaf is a non-profit organization with its membership comprising all the National Associations of the Deaf throughout Europe. Its goal is to maintain dialogues on deaf issues that are raised at the European Union level.

The European Union of the Deaf monitors the recognition status of sign language in all European countries. It also encourages empowerment through communication and information technology, promotes equality in education and employment, and disseminates information quickly to their members on relevant developments on deafness and sign language (European Union of the Deaf, 2010). European Union of the Deaf focuses on the recognition status of sign language in all European countries and there is no mention of its philosophies or policy statement on the use of cochlear implant on its website.

Summary of advocacy organizations, government agencies, and international affiliations

These major organizations, agencies, and affiliations at national and international levels are important to Sweden in development of bilingualism policy and the growth of cochlear implant recipients. The Swedish National Association of the Deaf (SDR) advocates and protects the use of sign language in the deaf community. Regardless of the choices each individual deaf person makes as whether to get cochlear implants or hearing aids, the right to the use of sign language is protected with the support of SDR. SDR serves on the Nordic Deaf Councils to exchange information with other Scandinavian countries and promote sign language. Barnplantorna collects and shares information on the various hearing assistive devices such as hearing aids and cochlear implants for the deaf community and for parents of deaf children. Barnplantorna also collaborates with other organizations such as European Union of Cochlear Implant Users (Euro-CIU) to foster the use of cochlear implants in development of speech. The Swedish National Agency for Education focuses on education policies for all children in compulsory

education. Bilingualism in special schools is encouraged. The Equality Ombudsman makes sure that each individual with disabilities is respected and has access to education or to the resources they need such as interpreting services or cochlear implants. The European Union of the Deaf collects information about the deaf community in each country. These organizations and agencies help with the development of bilingualism policy in Sweden and the growth of cochlear implants use.

2.4 The educational system in Sweden

This section will discuss the compulsory and special schools within the educational system in Sweden. The Skolverket regulates all schools. The National Agency for Special Needs Education and Schools provides support to schools that have students with disabilities.

Skolverket, the Swedish National Agency for Education

The school system in Sweden is monitored and regulated by the Swedish National Agency for Education (Skolverket) as described in the Education Act of 1985. Skolverket, a central administrative authority, defines the national goals and guidelines for all education from children to adults. The municipalities and schools have the flexibility to establish certain regulations within their region as long as the educational performances or outcomes meet the objectives by Skolverket. Skolverket, then, communicates its findings in its reports to the Swedish parliament and the government. There are public schools that children attend for free: Sami schools (for the native Scandinavians), compulsory schools (regular schools), and special schools (for children

with additional disabilities). There are independent schools that operate around the country but they must be approved by Skolverket to function under different regulations established by the municipalities. Through this recognition, the independent schools will be allowed grants from its regional municipalities for students to attend (Skolverket, 2009b).

About the Education Act of 1985

The Education Act of 1985 is for all children, youth and adults to have equal access to education. Skolverket is the sole authority to review and develop policy within the education system. The government sets national objectives for the schools to achieve, and the municipalities work with the schools locally on appropriate regulations. Syllabi are given to the teachers to interpret and create new teaching methods based on the framework given (Skolverket, 2009b). There is a specific section in the Education Act for the deaf community that allows for special schools to function for deaf students who cannot attend other regular schools because sign language is their main form of communication (The Education Act of 1985:1100). Bilingualism began in 1983 for special schools where Swedish Sign Language is a subject of its own and is the educational language for the deaf. The government supported bilingualism further with an addition to the curriculum in 1994 that deaf students should use both languages in the classroom with sign language as being of fundamental importance for linguistic development (The Swedish Institute for Special Needs Education, 2007; Mason, 1994). It was also emphasized that teachers and staff members in schools should be fluent in sign language. Since then, teachers in special schools and parents were offered Swedish Sign Language courses (Gibson, Mason, & Small, 1997; Pribanić, 2006). The Education Act stated that all compulsory

education is free to the students including those in special schools. The state is responsible to provide academic materials, tools, meals, and transportation for students attending special schools (The Education Act of 1985:1100). Also, for students who do not live near the schools, the schools must provide residence and recreational activities at no charge to the student (Specialpedagogiska skolmyndigheten, 2007).

Compulsory education in schools

Compulsory education includes regular schools, Sami schools (for the native Scandinavians), special schools, and programs for learning disabilities. Children attending regular schools are between the ages of 7 to 16 years for their first 9 years of education (not including preschool). However, students attending special schools have an additional year added to their curriculum for linguistic development of both Swedish Sign Language and Swedish. Regular schools run five days a week for 40 weeks starting at the end of August and until the beginning of June. Children have the right to choose any of the schools in the country, and most of them attend a municipal school close to home (Skolverket, 2006; Swedish Institute, October 2009).

For deaf students attending regular schools, a majority of them are placed in special classes with individual tutoring (Ohlson, 1970). Support-services vary among the deaf individuals such as a personal assistant who signs (Angerby, 2005). Classrooms may be arranged in U-form where students can see each other, especially helpful for the deaf students. There are "technical amplification systems where the hearing aid can be set to take in only the teacher's microphone, enabling the majority to follow the teacher's discourse and diminish the impact of disturbing noise" (Nordén, Tvingstedt, & Äng,

1984, p.80).

Before deaf students are admitted into the regular school, their abilities and qualifications are evaluated. In the past students with minor hearing loss (less than 30 dB) were placed in special classes within regular schools. Children with moderate hearing loss (between 30 and 60 dB hearing loss) were placed in a school for the hard of hearing in Orebro. Children with severe and profound deafness (more than 60 dB hearing loss) were placed in special schools such as Manillaskolan (Dolanský, 1967; Ohlson, 1970). What was not clear to the researcher was the placement of deaf and hard of hearing students in both regular and special schools. In personal communication with Dr. DeCaro and Mrs. Mudgett-DeCaro of their visit to Sweden in 1999, they observed in special schools that deaf students were separated in total communication (signing and speaking at the same time) classes and hard of hearing students were separated in oral communication classes with teachers who use a microphone, possibly through the FM unit or hearing loop system (DeCaro & Mudgett-DeCaro, personal communication, December 21, 2010). This could be similar for regular schools with a special department for the deaf. Many sources cited different classroom settings for the deaf student so there is no clear definition on how these deaf students were integrated. Currently, deaf students can choose any school to attend, and the state will provide the accommodations depending on the needs of each individual (Skolverket, 2006).

Special schools

Specialskola, or Special school in Swedish, is a bilingual school for the deaf. Both Swedish Sign Language (SSL) and Swedish (written and spoken) are used in instruction.

Deaf students are expected to learn both within their first year of compulsory education and then follow the typical 9-year education that any student would in a regular school. Altogether for these students it means 10 years of education. This includes learning a foreign language, most likely English (Skolverket, 2006).

The first school for the deaf in Sweden, Manillaskolan, was established in 1809 in Stockholm using hand-alphabet or finger spelling and sign language as the teaching method. During this early period of deaf education in Sweden, many changes were made in using the monolingual approach in teaching of the deaf. Many teachers struggled to choose between manual sign or an oral method. It was announced to the world at the Milan Conference of 1880 that the oral method was the appropriate way of educating the deaf although it was heavily debated that sign language had its benefits too (Foster et al., 2003; Bagga-Gupta & Domfors, 2003). Manillaskolan continued to maintain their teaching tradition in sign language (Specialpedagogiska skolmyndigheten, 2008). Shawn Davies wrote in her 1991 article, *The Transition Toward Bilingualism Education of Deaf Children in Sweden and Denmark: Perspectives on Language*, that "after all the years of strict oralism, there was so much negative feeling toward speech training that there are now very few trained speech teachers in the system" (1991). It is unknown as to when and for how long the other Swedish schools used oral methods after the Milan conference of 1880.

Integration of deaf students resulted through the "Contact Hypothesis" by Gordon W. Allport in 1954, which brought the Swedish community into experimenting and integrating children with disabilities into the regular classroom. It was assumed that integration of all children might improve communication skills and social relationships

(Nordén, Tvingstedt, & Äng, 1984). As a result of this hypothesis, the Swedish schools started integrating a majority of the deaf children into regular schools during the 1960s. Thus, no further special schools were built for the deaf (Ohlson, 1970). In the late 1970s, about 73% of the deaf students were placed in regular schools while the remainder (27%) were placed in special schools (Nordén, Tvingstedt, & Äng, 1984). This was a struggle for many students who relied on visual information. In 1973, Shawn Davies cited an observation by Brita Bergman, a sign language linguist who stated that "signed Swedish" (a different grammatical structure than the Swedish Sign Language) was inefficient and that the natural sign language, the Swedish Sign Language, could be completely mastered by deaf children before the age of three. Bergman's observation helped pave the way for bilingual approach in deaf education. Then in 1981, it was declared that Swedish Sign Language was the natural language of the deaf, and bilingualism became a policy for educating the deaf students (Mason, 1994; Davies, 1991).

Pribanić summarized in her 2006 article, *Sign Language and Deaf Education: A new tradition,* published in the Sign Language and Linguistics journal, that the current educational method for a deaf student learning both languages is as follows:

> Swedish Sign Language and spoken Swedish were taught as separate subjects. Swedish was taught as a second language, in much the same way as it is taught to immigrants. It is essential to keep the two languages apart from each other. Spoken and written words may sometimes correspond to a sign, but more often a single sign corresponds to a Swedish phrase or even a whole sentence. After many years of bilingual education, Swedish researchers discovered that many of the problems that deaf students encounter when learning Swedish as a second

> language resemble problems that non-native speakers have learning Swedish. The goal then was, and still is, to prepare deaf students to read well enough to have a solid foundation for acquiring knowledge, information and experience through all kinds of printed materials. At the same time it is also important to prepare deaf children for an adult life where they can be integrated into society. (p. 244).

Since July 1, 2000 six special schools have been regulated under the Special School Authority (SPM). In the same year, Ekeskolan (in Orebro) and Hallsboskolan (in Stockholm) were transformed into resource centers under the Swedish Institute for Special Needs Education. Both the Special School Authority and the Swedish Institute for Special Needs Education merged all eight schools under one agency, the National Agency for Special Schools (Skolverket, 2006).

In a 2005 report by Skolverket to the FEAPDA council by presenter Karen Angerby, she stated that there were about 600 students in special schools. Also in 2005, about 70% of the deaf children born in Sweden received cochlear implants (Angerby, 2005). In *Descriptive data on childcare, schools and adult education in Sweden* published by Skolverket, in the 2007-08 academic years, there were about 514 students in special schools. If school population data from 1995 to 2008 were analyzed, it may be assumed that the decline in enrollment of deaf students attending special schools may be because of the growth in the use of cochlear implants in deaf children, which caused some students to transfer to regular schools. According to Angerby (2005), low birth rates and cochlear implants may have influenced the slight decrease in enrollment for special schools. This may or may not be true depending on individual basis. The

researcher analyzed further into the century of student population data and found that there was a trend for student population, which will be explained in Objective 3 section below.

Teachers of the Deaf

After the recognition of sign language in 1981, teachers of the deaf were required to be fluent in Swedish Sign Language. Later, a parliamentary decision in 1988 created a new teacher's training program to help support all schools' teachers in receiving "the equivalent of a half term of study in special needs education" (Skolverket, 2006). Training in Swedish Sign Language was given to existing teachers in their schools. To become a qualified Sign Bilingual teacher, students in this field must attend three to four years of coursework at the University of Stockholm (Angerby, 2005). The teachers of the deaf sometimes devoted their time to creating new educational materials to adapt to the needs of the deaf students. More audiovisual aids were created in Swedish Schools as a result of this program (International Congress on Education of the Deaf, 1970). There are two support associations for the teachers of the deaf students: The Swedish Association for Educators of the Deaf and the European Federation of Associations of Teachers of the Deaf (FEAPDA) (Angerby, 2005).

The Swedish Institute for Special Needs Education

The Swedish Institute for Special Needs Education works with municipalities and schools in providing special needs support to students and parents so that the students with disabilities receive the best education possible. The institute has a resource center

that produces and distributes educational materials to schools for special needs students (Skolverket, 2006). The task of the Institute is not to take over the responsibilities of the municipalities but to provide support when needed (The Swedish Institute for Special Needs Education, 2007).

On July 1, 2008, the National Agency for Special Needs Education and Schools was established to merge the former National Agency for Special Educational Support, the Swedish Institute for Special Needs Education, and the National Agency for Special Schools for the Deaf under one central administrative agency. The main goal of this agency is to "ensure that children, young people and adults with disabilities will be able to develop and receive an education based on equality, participation, and accessibility" (National Agency for Special Needs Education and Schools, 2008).

The Swedish National Agency for Education oversees all compulsory education, including special schools, making sure that all children have equal access to education. The deaf students are allowed to choose any regular schools with accommodations. If necessary, the deaf students may choose to attend special schools where bilingualism of Swedish Sign Language and spoken Swedish are used in instructions. Teachers of the deaf must be fluent in Swedish Sign Language and if needed, sign language training is given at their school. The National Agency for Special Needs Education and Schools works with students with disabilities to make sure that they received equal access to quality education.

2.5 Access services for the Deaf

Access to information is important to deaf citizens. Interpreters, personal assistants and captioning on TVs are provided to the community through special funding by the Swedish government.

Interpreters

The need for sign language interpreters in the deaf community was first brought up in 1947 for legal proceedings (Niska, 2004). It took the Swedish Parliament 21 years to consider providing money for interpreting services on an experimental basis. For the first time in 1969, the government employed sign language interpreters. During the 1970s, sign language interpreters were slowly employed throughout the country (Niska, 2004). After the recognition of Swedish Sign Language in 1981, the training program for sign language interpreters was introduced and expanded. The Swedish Institute for the Handicapped organized recommendations to the county councils on how the services should function. The demand for interpreters was great in business arrangements, medical consultations, lectures and conferences (Fransson, 1984).

Established in 1986 at Stockholm University, the Institute for Interpretation and Translation Studies (TOI) was responsible for university level education in translation and interpreting, allocating funds for training of public service interpreters, and monitoring the training resources for adult education associations and other colleges offering sign language courses that may lead to interpreting professions. Interpreting services started before the training program was established at Stockholm University.

TOI were organized in 1968 to help facilitate communication between immigrants and the government. In 1986, the government decided to assign Stockholm University to be the primary university to train most of the community interpreters (Niska, 2004). In 2003, an estimated 5,000 community interpreters existed in Sweden with over 100 working languages but only 825 were authorized by Sweden (Niska, 2004). These interpreters were employed throughout the country and under the Health and Medical Services Act; all county councils are responsible to provide funds for these interpreting services. In 2004, there were about 60 interpreter service agencies operating in Sweden. About a third of these agencies were privately owned and the rest operated by towns and municipalities (Niska, 2004). In addition, there were 450 sign language interpreters in Sweden, but the demands were still high in 2004 (Niska, 2004). About 200 students take sign language courses every year. Before entering the interpreting field, students must take an introductory two-year sign language program then apply to the interpreting program for another two years. About 40 students continue onto the interpreting program each year (Niska, 2004).

Sign language interpreting is not offered in special schools because teachers use sign language as the main form of communication. At the university level, students will be assigned interpreters for classes, seminars, and group discussions; and this is free of charge to the students. In 2004, there were about 50 interpreters at the universities (Niska, 2004).

Personal assistants

Deaf students are placed in many different schools. Students in special schools do

not need interpreters because instruction is in Swedish Sign Language. For those in regular schools, deaf students are placed near the teachers, but they may be missing out on information from their peers. These students can request a personal assistant to help facilitate the information that they may have missed. It is not clear whether the personal assistant acts as an interpreter. The personal assistant observes a regular classroom with the deaf students and sometimes signs for the students any information they may have missed from their peers and teachers. The Education Act allows students with special needs to request a personal assistant (The Swedish Institute for Special Needs Education, 2007).

Captioning on TVs

In 1978, the Riksdag commissioned Swedish Television to design a captioning system for the deaf on televisions. Not only would the deaf benefit from these subtitled programs, but also senior citizens and immigrants needed foreign translations to many of the shows on the networks from Finland and Great Britain. By 1984, captioning on television (formerly called text-TVs) was developed to make shows accessible to roughly 3 million viewers (out of 8 million at that time). However, captioning was provided with limited funding so not all shows were subtitled on television. Swedish Television did captioning of shows that appealed to the highest interests of its viewers (Frohm, 1984). The Swedish parliament mandated new TV programs to be at least 50% captioned by 2005 (Hear It, 2009).

Summary of access services for the deaf

The deaf community in Sweden is offered a variety of access supports such as interpreters, personal assistants, and captioning on TVs. The Institute for Interpretation and Translation Studies (TOI) allocates funds for training of public service interpreters for the deaf community. Sign Language interpreters in special schools are not needed because teachers are required to be fluent in sign language. If a deaf student were to attend a regular school, a personal assistant is given to make sure that information in classes is not missed. In addition to the access support that deaf students receive, there are captioning on television.

2.6 Deaf community and identities

Sweden has a bilingual environment for the deaf using Swedish Sign Language and written Swedish. As a result, the deaf community continues to grow and change through new technologies and social interaction. When cochlear implants were introduced to Swedish deaf children in 1995, they caused a nation-wide dialogue among the various members of the community about the use of such technology for social development and language development.

Bilingualism in the deaf community

When bilingualism became the Swedish policy in 1981, many teachers and parents felt that this law gave support for language development in deaf children. Most parents were willing to learn the deaf child's language, Swedish Sign Language, because

society as a whole has the responsibility to maintain and support bilingualism in schools and at home (Davies, 1991). Therefore, the deaf child and their parents must learn Swedish Sign Language as soon as possible so that parents can stimulate and participate in their children's education. Preschool teachers use sign language to interact with their students, which creates a positive influence on children's ability to maintain and learn their language. Consequently, the child was allowed to acquire important social skills when interacting with peers (Sveriges Dövas Riksförbund, 2007a). The delay in signed and written and/or spoken language development may make the child's peer interaction more complex (Preisler & Ahlström, 1997). Without the ability to make friends, the child may not be able to develop his or her own identity. He or she will not be able to understand the essentials in building strong relationships with peers. Thus, starting the bilingual environment of signing and spoken Swedish in preschool promotes each child to connect with others to grow intellectually and socially (Sveriges Dövas Riksförbund, 2007a). In Sweden, almost all parents with deaf children know Swedish Sign Language. Attitude plays a very important role in fostering this relationship between the parents and the child. Parents came to accept that Swedish Sign Language is the natural language of deaf children because Sweden encourages it. With a positive attitude and parents receiving support in acquiring the Swedish Sign Language, the child quickly connects and learns more from their peers in society (Davies, 1991).

However with hard of hearing children the situation was less clear. Sven Eric Malmström presented in his 1984 report to congress in Stockholm criticizing the attitude among the hard of hearing community that:

It seems to me that the resources are being concentrated on trying to reach the

> goal of eliminating the consequences of the hearing impairment, or, if you like, to train the hard of hearing to be 'as much like the normally hearing' as possible… We have to realize that the negative attitude of the hard of hearing to their handicap is coming from the environment, from the general attitude to the hearing impairment. Therefore we have to help hard of hearing people to create a positive self-esteem and identity. (p. 30-31).

Hard of hearing children are those who need some type of assistive hearing devices such as hearing aids. Hard of hearing children in Swedish schools are considered those who can function without a sign language interpreter. Many of these children have developed speech and can manage conversations in a quiet environment. Hard of hearing children using sign language is helpful in a noisy environment such as outdoors, restaurants, or public transportation (Sveriges Dövas Riksförbund, 2007a).

Deaf children acquire Swedish Sign Language and Swedish in special schools. First without relying on speech, the deaf children were taught to read and write. "Sign language can be used to convey and discuss the written language; explanations and clarification can be signed" socially (Sveriges Dövas Riksförbund, 2007a). Swedish researchers believe that sign language is the first step into normal language development before written Swedish. When these deaf children develop enough to understand and learn, their speech can be perceived using technical aids when communicating with others. Sign language gives the child full access to communication then creates the opportunity for spoken Swedish to develop in later stages after the child discovers and understands the information that he or she is receiving through technical aids socially (Sveriges Dövas Riksförbund, 2007a).

The emergence of cochlear implant (CI) technology into Sweden, a timeline

The first experiment on the auditory nerve was performed by a scientist named Lundberg who attempted the direct electrical stimulation of the auditory nerve in the ear in 1950. Electrical stimulation studies were conducted with several animals and then were tested on humans. In 1961, two scientists, House and Urban, implanted a single electrode (e.g., single channel device) into three patients for a short period of time and they were able to perceive environmental sounds and control their own voices better, but they did not understand speech (Glasscock & Haynes, 1994). The experiments on animals and patients continued throughout the 1970s creating different designs and multiple electrode (e.g., multi-channel) devices to stimulate the auditory nerves. Clinical trials were performed and cochlear implantation was given to patients in the 1980s. The United States Food and Drug Administration approved the 3M single channel speech processor model in 1983 for adults and then later approved the Cochlear Corporations multi-channel device for children in 1990 after several series of clinical testing in adults demonstrated the ability to understand speech without speech reading (Preisler, 2001; Zwolan & Thomas, 2009). Children with profound deafness ranging in age from 2 to 17 were recruited and tested. In 1990, 80 children were given cochlear implants (Grayden & Clark, 2006). Improvements in spoken language development and cochlear implant designs resulted in more children receiving cochlear implants. The number of cochlear implants in children worldwide increased to 800 in 1992 and 2,600 by 1993. By January 1999, 11,000 children worldwide received cochlear implants (Preisler, 2001). In 2006, there were more than 90,000 cochlear implants users internationally (Grayden &Clark,

2006). In 2009, there were approximately 188,000 people worldwide that have received a cochlear implant (NIDCD, 2009).

The research for cochlear implants in deaf children in Sweden started in 1995. By 2001, approximately 180 deaf children in Sweden had received cochlear implants (Preisler, Tvingstedt, & Ahlström, 2002). In 2004, approximately 350 children in Sweden had cochlear implants (Willstedt-Svensson, Lofqvist, Almqvist, & Sahlen, 2004). According to Barnplantorna's 2009 statistics, there were 569 children with cochlear implants in Sweden (Barnplantorna, 2009d). In their January 2010 report, 628 children in Sweden had cochlear implants (Barnplantorna, 2010b).

Identities in the deaf community

The international view of deafness varies among countries. Deafness can be seen as a culture of its own using different methods of communication such as sign language. Deafness can also be seen as a medical condition that can be solved by certain treatments such as hearing aids or cochlear implants. Several countries shared their views and candidacy criteria for cochlear implants such as age requirements, levels of hearing loss, lack of benefit from hearing aids, and methods of communication before and after implants (Preisler, 2001). Sweden encourages the family to establish sign language communication mode with deaf children. For the CI to be successful, speech training is crucial. The children's Swedish language development relies on oral education. However, the gain in auditory perception and production does not necessarily lead to participation in spoken conversations. Studies show that some children have difficulties in taking part of natural conversations with more than one person at a time (Preisler, Tvingstedt, &

Ahlström, 2002).

The studies presented to the Council of Europe showed the positive effects of sign language in deaf children, not only for communication reasons but also for emotional, social, and language learning as well. It was suggested that children with cochlear implant use sign language in communicating their ideas and thoughts. It was suggested that they read and write to learn the Swedish language before they start speaking Swedish. It was also recommended that more follow-up studies and research be undertaken to evaluate the effect of implants on children's emotional, social, communicative and cognitive development and language, speech, and hearing development (Preisler, Tvingstedt, & Ahlström, 2002). Children with cochlear implants developed a 'bicultural identity' by using both sign language and spoken Swedish to communicate. "Nine of 10 deaf children live in hearing households where they are exposed to speech daily" (Preisler, 2001).

In Sweden there are many different identities within the deaf community. There are deaf people who sign and speak. There are some that use technical aids such as hearing aids, middle ear implants, or cochlear implants. Being deaf or hard of hearing in Sweden is a social position with the law-given privilege to use sign language in an environment designed for the hearing. Many deaf children are mainstreamed in schools with the majority who are hearing. These children need to identify with others who share the same experiences (Gustavsson, 1980/1984). Some hard of hearing children with hearing aids may reject using them because they discover that they are different from other children. There are clubs for the deaf where one could share and accept their hearing loss as part of their identity and encourage development of positive self-esteem

(Malmström, 1984). In a 2005 study conducted by Preisler, Tvingstedt, & Ahlström, a 10.5 year old girl shared her insight on her cochlear implant identity, "I would like to be hard of hearing. But (with) CI… you need a lot of patience, and you need to use it all the time… Without the implant I can't hear at all… otherwise I am deaf" (p.265). There are various people with hearing loss in Sweden and they have distinguished their identity apart from others either by labeling themselves as deaf, hard of hearing, or cochlear implant users.

Deaf people do not see their hearing loss as a "devastating disability but as some kind of ethnic identity. Hearing parents of deaf children do not see it this way; they want their children to hear and speak at almost any cost" (Ramsey, 2000). Some deaf children in regular schools rely on the use of sign language with their teachers or personal assistant in the classroom. Some use technical aids to receive auditory information and do not need an interpreter (Davies, 1991). Swedish National Association of the Deaf considers 'signing deaf' as anyone who has a profound hearing loss (Sveriges Dövas Riksförbund, 2010a).

Assistive hearing devices among the deaf children vary from using hearing aids, cochlear implants, or neither technology. Hearing aids are used among the deaf children in communication if their hearing loss is no greater than 60 dB (Nordén, Tvingstedt, & Äng, 1984). In addition, there is a technical amplification system in the classroom where hearing aid can be set to only to take in teacher's microphone to diminish the impact of surrounding noise and focus on the teacher's lecture (Nordén, Tvingstedt, & Äng, 1984).

Summary of deaf communities and identities

In Sweden, the deaf and hearing communities both have views that are influenced by bilingualism and cochlear implant technology. In the deaf community, hearing loss is considered the 'norm' and they have developed a culture using Swedish Sign Language as their main form of communication as well as spoken Swedish. No matter what hearing assistive devices a deaf person uses, the deaf community promotes and protects the use of sign language. On the other hand, technologies influence the perspectives of the hearing peers such as parents and doctors. Deafness is not the 'norm' in the hearing community, therefore, the medical community conducts research to find ways to restore hearing loss through new technologies. Cochlear implants have more benefits than hearing aids in development of speech. Like hearing aids in the past, the growth of cochlear implant users may change the attitudes and perspectives of both deaf and hearing communities.

2.7 The Swedish health care system, process for obtaining a cochlear implant, and the development of language

The government, agencies, and policies in Swedish health care

Approximately 9.2 million (2008) people living in Sweden have equal access to the health care system. The health care system is decentralized through the county councils and municipalities (Regeringskansliet: Government Offices of Sweden, 2006; Swedish Institute, 2008). The Swedish government establishes guidelines and a political agenda for health and medical care. Statistics from the National Board of Health and Welfare in 1999 showed that there were 1,860,000 people in Sweden who had some type

of functional impairment, about 21 percent of the total Swedish population. From this statistic, 435,000 citizens were hearing impaired, and were older than the age of 16 (Socialstyrelsen, 2008). The researcher could not find statistics for school children under the age of 16.

The Swedish disability policy helped shape Sweden over the past 50 years. The Social Insurance benefits and legislations were made to give care to all citizens equally. However, there are some disabled citizens that require a separate legislation to support and provide accommodations for special needs that fall outside of the health care system. A special need such as habilitation, rehabilitation and technical aids varies among individuals. The *Act Concerning Support and Services to Persons with Certain Functional Impairments,* gives authority to the municipalities to provide accommodations or technical aids that are not normally covered by health and medical services (e.g., high quality electric wheelchairs or cochlear implants) (Regeringskansliet: Government Offices of Sweden, 2007).

The medical perspective in Sweden on disability is defined as "difficulties encountered by the individual in daily life, for physical or mental reasons" (Regeringskansliet: Government Offices of Sweden, 2007). The goal of the health care system in Sweden is to help a person become one whole being. The disability policy calls for integration and less institution affiliation for these disabled citizens. During the 1960s, about 50,000 institutions housed many groups of disabled citizens. However, that number has reduced to 5,000 institutions in 2007 showing that the government has encouraged disabled citizens to be more independent and active participants in society (Regeringskansliet: Government Offices of Sweden, 2007). This is the similar for the

number of special schools. Sweden has permitted eight special schools for the deaf so that they could receive additional supports that regular schools could not provide. However, Sweden encourages integrating deaf students into regular schools.

The Ministry of Health and Social Affairs, one of twelve ministries under the Swedish government, oversees all health and medical care, public health, social insurance, policy for elderly and individuals with disabilities. It sets objectives for health care and helps government carry out its policies. The welfare agency, under the Ministry of Health and Social Affairs, collects and analyzes government data regarding health and official statistics. The welfare agency also works with disability policy to make sure that all citizens have access to the care they need (Socialstyrelsen, 2008; Swedish Institute, 2007).

Hospital procedures for obtaining a cochlear implant

The hospitals in Sweden have a procedure for checking on every newborn to ensure that each is in good health. Early neonatal screenings are given to newborns so that doctors can detect hearing loss shortly after birth and give parents educational intervention options (Angerby, 2005). Deafness is regarded as a medical problem, which can be treated by using cochlear implant (CI). The main reason for implementing CI is that it is easier for the child to develop oral communication and gain access to the hearing world. There are criteria throughout the world for selection of patients eligible for a cochlear implant, of which hearing loss must be severe or profound. The level of hearing loss is defined and measured in decibels (dB). For example, Cochlear Ltd.'s candidacy criterion for cochlear implant is children under two years of age must have a severe to

profound sensorineural hearing loss in both ears, or at least 90 dB (Johnston, Durieux-Smith, Angus, O'Connor, Fitzpatrick, 2009; Cochlear Americas, 2010). However, younger children have been implanted early between 6 and 12 months of age depending on specific medical conditions (e.g., meningitis) and hospital policy (Preisler, 2001; Cooper & Craddock, 2006; Kim, Chang, & Lim, 2000; Zwolan, 2008; Zwolan & Thomas, 2009). As soon as a newborn is found with a hearing loss, the family is referred to the cochlear implant team and entitled to 240 hours of sign language courses (Angerby, 2005). In Sweden, the cochlear implant team consists of a surgeon, audiologist, teacher of the deaf, speech and language therapist, and a psychologist. This group of experts informs the parents about the procedure for obtaining a cochlear implant and the importance of incorporating sign language in their life (Cooper & Craddock, 2006). Once the parents of a deaf child are motivated to learn sign language and have decided to have a cochlear implant for their child, the process for surgery begins (Preisler, 2001). The child undergoes surgery for cochlear implantation and sometimes is released the next day. It takes about a week to heal. It is expected that anyone who receives a cochlear implant might need further surgery for an upgrade during his or her lifetime (Cooper & Craddock, 2006).

Cost of cochlear implants

In Sweden, about 100,000 children are born each year and about 100 to 200 of these children have some hearing loss and are eligible for technical aids such as hearing aids or cochlear implants (The Swedish Council on Technology Assessment in Health Care, 2006). Cochlear implant surgery (unilateral) costs around SEK 350,000

(approximately $50,000) or sometimes SEK 600,000 (approximately $86,000) for two (bilateral) if both are implanted at the same time. The cost is covered by the government and free for the deaf person. A researcher from El-Maghraby Eye and Ear Hospital, Ahmed Handoussa, wrote in his article *Cochlear Reimplantation,* that "cochlear implant can be more effective than ordinary hearing aids on the development of children's perception and production of speech. A gain in auditory perception/production does not necessarily mean a corresponding gain in taking part in spoken conversations" (Handoussa, 2000). Swedish researchers are still studying the effectiveness of cochlear implants since the first adult implant patients in Sweden during the 1980s. In 2004, approximately 350 children in Sweden had cochlear implants and the Swedish researchers felt that this number of children was not enough to do a comparable and reliable study on the use of a cochlear implant (Willstedt-Svensson, Lofqvist, Almqvist, & Sahlen, 2004). In consideration of the fact that there were 569 Swedish children with cochlear implants in 2009, this would be a good research study on the effectiveness of cochlear implants and bilingualism.

Language development theories in using a cochlear implant

The world is full of symbols representing different things and a child grows to develop human interaction through language acquisition. A hearing child picks up environmental sounds around him or her, which is a significant source of information. Like any newborn, they also see the vast world around them. Language acquisition can be developed visually and auditorially once the child understands this world of symbols (Hallberg & Ringdahl, 2004; Preisler, Tvingstedt, & Ahlström, 2002). There is a

theoretical assumption of "critical stage" or "critical period" in spoken language development. It is assumed that there is a certain age period within which a child develops biologically and intellectually. The first four or five years of a child's life are considered the critical period where the primary language is developed and mastered (Preisler, Tvingstedt, & Ahlström, 2002). In addition to the critical period theory, it was found that infants look to their mother's facial expressions during the first 4 months to observe emotions or what the mother might be thinking about. The infant continues studying the mother's facial expressions until age 8 to 10 months when the infant have finally understood the meaning of the mother's facial expressions (Preisler, Tvingstedt, & Ahlström, 2002). Researchers felt that it was important to detect any barriers that a child may have so proper care can be given to assist the child's acquisition of the spoken language (Handoussa, 2000). The child imitates sounds around him or her and develops the spoken language in phonological memory. A cochlear implant can support this spoken language development (Willstedt-Svensson, Lofqvist, Almqvist, & Sahlen 2004; Belzner & Seal, 2009). In Connor, Hieber, Arts, and Zwolan's research, *Speech, Vocabulary, and the Education of Children Using Cochlear Implants: Oral or Total Communication*, it states that "children in TC (total communication) achieved significantly higher receptive spoken vocabulary scores than children in the OC (oral communication) group if they received their implant before the age of 5 years" (2000). In addition, Geers, Nicholas, and Sedey conducted a study, *Language Skills of Children with Early Cochlear Implantation*, and found out that "receiving an implant at 2 or 3 yrs of age did not appear to provide any significant linguistic advantage over receiving it at age 4 or 5" (Geers, Nicholas, & Sedey, 2003). This was possibly because deaf children were

able to perceive speech and sounds better when implanted at a younger age, but when it comes to developing the linguistic skills, they will learn them most likely at the same level as a hearing person in preschool or elementary school. Geers, Nicholas, and Sedey included the environmental factors of deaf children in an oral environment versus total communication (signing and speaking at the same time) environment and found that there was not a significant difference in development performance of the English language (Geers, Nicholas, & Sedey, 2003). American Sign Language and the English language both have two different grammatical structures so when deaf children use either the oral method or total communication in learning the English language, they are still able to understand speech and sounds using cochlear implants with or without sign language. Referring back to Connor, Hieber, Arts, and Zwolan's research, they claimed that oral communication helped deaf children develop better speech scores while those in total communication had better vocabulary scores (Connor, Hieber, Arts, & Zwolan, 2000). There is a consensus among various researchers that implanting at a young age improves speech perception and production more than those implanted later in life. On the other hand, the debate continues around the world on when the best time is for implantation. A longitudinal study published from 2000 through 2007 contains a collection of research within the United States by Belzner and Seal to show what has been conducted, the age of implantation, and the outcomes of using cochlear implants. One study within this collection by Hammes, Novak, Rotz, Willis, Edmondson, and Thomas stated that "children who received their implant before 30 months of age were more likely to acquire spoken language skills... Children implanted at 18 months or younger achieved the higher spoken language outcomes and children implanted at older than 48 months achieved

lower outcome scores" (Bezner & Seal, 2009). Most children receive a cochlear implant (CI) before the age of 5 years, but more and more children are having this procedure as early as 12 to 18 months and even as young as 6 months (Willstedt-Svensson, Lofqvist, Almqvist, & Sahlen 2004; Bezner & Seal, 2009; St. James, 2010). The goal that doctors have in mind is that the child be as "normal" as possible. In addition, doctors are recommending implanting cochlear implants in both ears for added benefits such as "sound localization, better hearing and background noise…" (St. James, 2010). If the child is born deaf, the doctor will prescribe technical aids, most likely the cochlear implant, so that the child can participate in the spoken environment as the family. Having an implant helps the child perceive the sounds from the environment, but the deaf child may need speech training to understand it. It was sometimes assumed by experts that sign language might hinder the development of spoken language (Preisler, 2001). However, there is not enough empirical evidence that supports the experts' opinion on the disadvantage of using sign language toward the development of spoken language. In Sweden, researchers continue to advocate for bilingual approach, which is sign language as the natural language of the deaf before and after implantation (Willstedt-Svensson, Lofqvist, Almqvist, & Sahlen, 2004).

Summary of the Swedish health care system, process for obtaining a cochlear implant, and the development of language

The health care system in Sweden has a method to support their disabled citizens through each level of government. The county council is responsible for cochlear implants in people with a severe to profound hearing loss. In some countries, the

candidacy criteria for age varies but in Sweden there are no specific age criteria for deaf infants because bilingualism in Sweden encourages the use of sign language and the development of speech to communicate. In Sweden, if cochlear implants help a deaf child with the development of speech then it is encouraged to have cochlear implants as early as possible.

2.8 Summary of literature review

The emergence of cochlear implant technology in Sweden has been a very interesting topic to study, especially with bilingualism as its policy for the deaf community. Many other countries have different approaches to educating the deaf. Some have taken the oral method, sign language, captioning, or use almost everything to get their messages across. Others have taken advantage of technology to restore hearing as much as possible such as hearing aids, cochlear implants or other assistive listening devices. Studying Sweden demonstrated a working system that helped their disabled citizens become more independent using tax dollars to cover medical expenses. There are 569 children in Sweden that have received cochlear implants, almost 90% of the students in special schools. This looks toward a new generational shift in Swedish community perspective on deafness. The Swedish government protected Swedish Sign Language so that technology will not diminish the culture that exists within the deaf community as well as the awareness of their own deaf identity as a ‘norm’ that has been valued by deaf people in Sweden. Does the emergence of cochlear implant technology in a bilingual environment improve the life of deaf children with their family and peers? It is important to continue studying the impact of technology on the lives of people today. Are there

some facets that the United States could adopt and benefit from the Swedish model? These questions posed will be discussed after the interpretation of answers from the questionnaires sent to hospitals, organizations, and agencies for the deaf in Sweden.

3.0 Methodology

3.1 Analytical framework and rationale

The thesis explores the emergence of cochlear implants technology impacting Sweden's environment toward existing disability policies and procedures in education, health care, and organizations serving deaf people. The research involved in-depth literature reviews, distribution of questionnaires, data collection, and interpretation of results. Before collecting any information of current circumstances of cochlear implants in Sweden, an in-depth literature review was conducted to learn about Sweden's history and the emergence of cochlear implant technology in its bilingual environment. After understanding the history and the process for getting cochlear implants in Sweden, the same three research objectives were used to create questionnaires as a guide for exploring the current situation in Sweden also providing a snapshot of occurrences in 2007. Questionnaires were distributed to five major community organizations/agencies and six regional hospitals. Data was collected and analyzed for review.

Research objectives

Three objectives were structured to guide this research:

1. Provide current documentation of criteria and processes for obtaining a cochlear implant.

2. Gather existing policy statements on cochlear implants from major community organizations serving deaf people.
3. Collect historical and current statistical data of the deaf population who have cochlear implants or hearing aids in compulsory education including special schools (first grade to ninth grade).

The first objective, to provide current documentation of criteria and processes for obtaining a cochlear implant was important to explore because countries around the world have different criteria and processes for receiving cochlear implants. This thesis explored hospital procedures and included a few questions. What does a patient go through to receive cochlear implants? How does the hospital inform its patients on the choices of technical devices such as cochlear implants or hearing aids? What are the cochlear candidacy criteria that determine eligibility for the procedure and how old must the patient be to receive a cochlear implant? In the literature review, researchers found that more children are receiving cochlear implants at a younger age. How were the parents informed on technical devices that lead to their decision to choose cochlear implants or hearing aids for their deaf child? A questionnaire with ten specific questions was tailored for the hospitals to share its procedure on educating its patients and the process for receiving cochlear implant. Only six Swedish hospitals in 2007 were identified to have provided cochlear implants to their patients: Uppsala University Hospital in Uppsala, Sahlgrenska University Hospital in Göteborg, The University Hospital in Linköping, Lund University Hospital in Lund, Karolinska University Hospital in Stockholm, and Norrlands Universitetssjukhus in Umeå.

The second objective was to gather existing policy statements on cochlear implants from major community organizations serving deaf people. Five major organizations/agencies were chosen to explore policy statements on cochlear implants: Sveriges Dövas Riksförbund (SDR) – *The Swedish National Association of the Deaf*, Skolverket – *The Swedish National Agency for Education*, Barnplantorna – *The Swedish Cochlear Implant Children Organization*, Riksförbundet (DHB) – *The Swedish National Association for Deaf, Hearing-Impaired and language-Impaired children,* and the Diskriminerings Ombudsmannen – *The Swedish Equality Ombudsman.* Each organization or agency serves the deaf community through its individual mission. As stated in section 2.3, SDR is an advocacy organization for the deaf community supporting the use of sign language and working with politicians on civil right issues. Barnplantorna is an advocacy organization for children who use technical aids such as cochlear implants. DHB is an advocacy organization mainly to support better quality education for deaf children. The Equality Ombudsman is a government agency that supports its disabled citizens and works with the deaf community on any issues they may have. Skolverket is a government agency that focuses on the education system for the entire population in Sweden and it works with special schools as well as integrating deaf students in regular schools. Each organization or agency may or may not have a policy statement on cochlear implants. All five organizations received the questionnaire consisting of six questions in English about its perspectives on cochlear implants, hearing aids, and Swedish sign language. As previously mentioned in Objective 1, a questionnaire with ten questions, similar to the questionnaire for the hospitals, was created to explore organizations' or agencies' knowledge of the process that a person

with hearing loss may go through and how he / she came to the decision as to which technical aids to use.

The third objective was to collect statistical data on the deaf population who used cochlear implants or hearing aids in compulsory education including special schools from first grade to ninth grade during the year 2007. It was wondered if the deaf children still sign when using cochlear implants or use a personal assistant (a person knowledgeable in sign language but not an interpreter) to receive missed information. Several research studies stated different statistics and the percentage of children with cochlear implants so it was important to find reliable publications (e.g., annual reports and public brochures). The Statistics Sweden (SCB) and the Swedish National Agency for Education are the two well-known agencies that report statistics on the Swedish population. An inquiry email was sent to both agencies to obtain statistics.

3. 2 Data collection techniques

Time table for questionnaire

Once questionnaires were developed and approved by the Institutional Review Board at Rochester Institute of Technology, corresponding with the subjects began. Sometimes contact information on the group's website was not up-to-date. Consequently, referrals or undeliverable messages were inevitable and expected. Once the appropriate representatives had responded, the questionnaire packet with the cover letters was sent electronically. The representatives were given a deadline to submit their responses. Sometimes a follow up reminder was needed. It was expected that it might take more than a month for the representatives to reply. Some took one month to reply, some were

extended to three months including follow up questions after the responses were received.

Respondents

There are several respondents that work closely with the deaf population: five organizations/agencies and six regional hospitals that perform cochlear implant surgery. A list of each subject and its website is given below.

Organizations/Agencies (5):

Sveriges Dövas Riksförbund (SDR) – *The Swedish National Association of the Deaf*
Website: http://www.sdrf.se/sdr/
Skolverket – *The Swedish National Agency for Education*
Website: http://www.skolverket.se/
Barnplantorna – *The Swedish Cochlear Implant Children Organization*
Website: http://www.barnplantorna.se/
Riksförbundet (DHB) – *The Swedish National Association for Deaf, Hearing-Impaired and language-Impaired children*
Website: http://www.dhb.se/
Handikappombudsmannen – *The Swedish Disability Ombudsman*
Website: http://www.ho.se/Tpl/StartPage____4.aspx

Hospitals (6):

Uppsala University Hospital (Uppsala)
Website: http://www.akademiska.se/
Sahlgrenska University Hospital (Göteborg)
Website: http://www.sahlgrenska.se/
The University Hospital in Linköping (Linköping)
Website: http://www.lio.se/
Lund University Hospital (Lund)
Website: www.usil.se
Karolinska University Hospital (Stockholm)
Website: http://www.karolinska.se
Norrlands Universitetssjukhus (Umeå)
Website: http://www.vll.se/

Questionnaires development and management

An electronic packet was created for each organization, agency, hospital, and manufacturer. The packet contained: cover letters from the committee chair, Dr. James DeCaro, and the researcher, Christopher Samp. The representative was asked for voluntary participation in the questionnaire process, a consent form to protect representative's identity from each group, and permission to share the results. Cover letters, consent forms, and questionnaires can be found in the Appendices. The packet was distributed to each subject by emailing the representative. Their contact information can be found through each subject's website. An inquiry was sent to the Webmaster if the representative's contact information could not be found on the website.

Rochester Institute of Technology (RIT) has an Institutional Review Board, which carefully reviewed the consent form and questionnaires because the research involved human subjects. RIT and the researcher want to protect the rights, safety, and welfare of the people who take part of this research. The researcher promised the subjects that their names and communication with the researcher will not be disclosed to anyone other than those on the committee. All communication between the researcher and the subjects through emails or regular mail will be destroyed after the research is completed. If the representative gives permission to cite the source, the researcher will maintain the information. The questionnaire packet and the communication between the researcher and the representative are printed in English. The researcher has no knowledge of the Swedish language and relies on materials available in English and using translations for information on the Internet. English is the 2nd language of Sweden and widely used and understood. Since people in Sweden understood English, there was no concern to the

researcher about the responses. Through the communication process, the questionnaires were filled out, unanswered, or referred to another person.

Limitations of data

Many of the publications were available in Swedish and very few were in English. The researcher relied on the representatives' knowledge of English and provided their response or publications in English. An online translator tool was helpful in some cases. However, it was not 100% reliable since it was noticed that part of the information was lost in translation and/or certain sentences were not translated properly.

4.0 Interpretation of results

4.1 Findings for Objective 1

Objective 1 is "*Provide current documentation of criteria and processes for obtaining a cochlear implant.*"

Representatives:

1. Karolinska University Hospital in Stockholm
2. Lund University Hospital in Lund
3. Norrlands Universitetssjukhus in Umeå
4. Sahlgrenska University Hospital in Göteborg
5. The University Hospital in Linköping
6. Uppsala University Hospital in Uppsala
7. One of the five organizations/agencies

Who responded?

A questionnaire regarding the process and criteria for cochlear implant candidacy was sent to six regional hospitals (see Appendix E). Three out of six hospitals responded to the questionnaire. Two hospitals responded to the emails but did not fill out the questionnaire after several referrals to different representatives. The remaining hospital did not respond, even after several attempts to reach different representatives within the hospital. Similar questions (Appendix D: Part 1) were sent out to five different organizations/agencies and only one filled out the questionnaire. To protect each representative's confidentiality, the responses of the three hospitals and one organization/agency will be referred to as Representative A, Representative B, Representative C, and Representative D in no particular order. The responses will be listed within each question followed by the interpretation of their responses.

Questionnaire Responses:

There are ten questions in the questionnaire about the procedure for detecting a hearing loss in a patient and once detected, the process that the patient goes through to get technical aids will be explained. The interpretation of the responses from the first three questions will be combined as one summary because each response leads from one question to another. Questions 4, 9 and 10 will have their own summary. The responses in Question 6 were referred to Question 5 because of the similarity in both questions. Thus, the responses in Question 6 have been eliminated but will be explained later in this document. The summary for Questions 7 and 8 will be combined as one.

Question 1 to 3 and summary:

Question 1: What is the standard procedure for a checkup of a patient's hearing loss?

Representative A:

A) Children: OAE-screening. ABR x 2 or more. Several behavioral tests until diagnosis is set.

B) Behavioral tests. If needed more tests (new ABR, with and without hearing aid - with noise).

Representative B:

Audiogram or distraction, audiometry for older children, otherwise OAE and ABR and ASSR, if necessary (over 6 mo. of age) under sedation. Otomicroscopy. Sometimes tympanometry. Observation of language development.

Representative C:

Concerning children in Sweden, all children are going through neonatal hearing screening at birth.

Representative D:

Depending on the age of the patient: distraction audiometry, play audiometry, OAE. In very small children: auditory steady state evoked potentials with click stimuli during natural rest. If any doubt regarding psychoacoustic measurements: ABR in general anaesthesia, sometimes ECoG. All children in need of hearing devices are cared for by the public health system, and most of the audiological check up is made in the public health system.

Question 2: How is the patient or the parents informed of the hearing loss?

Representative A:

The doctor (medical audiologist) informs the patient or parents. If it is a child a social worker is also involved in the information procedure.

Representative B:

By a physician, after the hearing tests by the pediatric audiologist. How the ear works, the probable diagnosis, degree of certainty in the assessment process. In case of substantial hearing loss, a psychosocial network (special educational teachers, psychologists, social workers) is introduced at the same time. They will call to personal and group information and other activities.

Representative C:

The doctor informs the parents if there is a hearing impairment. If candidate to cochlear implant then parents are referred to CI clinic for further tests. If the child only needs hearing aids then those are nowadays fitted already at the first months of the child's life (generally) in local hearing centre in hospital.

Representative D:

By the audiologic technician and by the medical audiologist. All families with a child in need of hearing aids will meet all members of the team… (Medical audiologist (also ENT surgeon), audiologic technician for children, engineer, teacher for the deaf, speech therapist (for some children), teacher of signed language (some children) and counselor).

Question 3: What referral was made to a patient when hearing loss was discovered?

Representative A:

For children: Referral to ophthalmologist and often to a paediatrician.

Representative B:

Psychosocial network, eye examination, pediatric neurologist at times. Often investigations regarding CMV, Connexin 26 or other causes of hearing loss.

Representative C:

Will refer to the local hearing centre in the nearest hospital. Important to note is that parents will meet a physiologist as well because of crisis when realizing they have a child with hearing impairment.

Representative D:

Besides to all team members there will be a referral to a pediatrician and to an ophtalmologist. Testing for congenital CMV infection and genetic testing of Connexin 26.

Summary of responses for Question 1 to 3:

In Sweden, all newborns are given the Universal Newborn Hearing Screening test to detect any deafness so that proper habilitation such as technical aids for the child and sign language courses for the family can be given. The test is usually given at the first month of the newborn's life for early intervention and to help the parents establish a way to connect with their child if found to have a hearing loss (The Swedish Council on Technology Assessment in Health Care [SBU], 2004; Gravel and Tocci, 1998). The cost for the test is SEK 240 (about $35) per child and this is covered by the health care system

with no cost to the family. Each test adds to the health care budget totaling approximately SEK 19 million (about $2.8 million) to assess all the newborns in 2004 (SBU, 2004).

The Universal Newborn Hearing Screening test protocol consists of knowing family history of hearing loss, identifying immediate illnesses, and testing the ear through devices such as OAE/ABR. Parents of newborns are asked if there are any family members with a hearing loss because it is possible that the hearing loss is genetic in the family. Further tests will be given if the infant is found with a hearing loss. The newborns are first tested through two different medical devices: OAE and ABR. Otoacoustic Emission (OAE) is the stimulation that occurs within the cochlea that emits low-level sound. A device, an earplug-like microphone, is placed in the infant's ear to measure the cochlea's response to sound and for the echo after sound is heard through the ear. The OAE test is usually given when the infant is sleeping. If there are no otoacoustic emissions then it is identified as possible hearing loss and an ABR test is followed up (Berke, 2007; Stach 1997). ABR is an abbreviation for Auditory Brainstem Response, which measures the responses in the auditory nerve; Cranial Nerve VIII of the brain by a device near the ear making clicking sounds. An earpiece sends the sounds through the ear and the electrodes placed on the scalp/earlobes tracks the sound moving from the ear to the brain. There must be minimal movement for this test to measure the neural functions (Berke, 2007; Stach, 1997; Prieve & Orlando , 1998). Performing an OAE and ABR testing averages 15 minutes per infant or may take up to 45 minutes for a restless infant (Spivak & Jupiter, 1998). A behavioral test is followed afterward where a trained audiologist observes the infant's body and head responses to sounds (University of California San Francisco Benioff Children's Hospital, 2010). If the infant is unable to

cooperate through the tests, then the Auditory Steady-State Response (ASSR) test is given. Similar to ABR, ASSR is given to the sedated infant and measures the neural response to the frequency of a tone to the brain by stimulating the tone on and off periodically (Stach, 2009). In rare cases, an ECoG or ECochG test is given to the infant only if previous tests through OAE, ABR, and ASSR showed no results of hearing loss or errors in measurement. ECochG is the common medical abbreviation for Electrocochleography, which is a method for acquiring responses from cochlear and auditory nerves by stimulation of sounds to the infant's inner ear by inserting the needle type electrode through the eardrum. This procedure can be very difficult and painful (Hall, 2006; Stach 1997; Hain & Rudisill, 2009). In Sweden, only OAE and ABR tests are routinely administered to infants for the identification of hearing loss. In the Swedish procedure, based upon the questionnaire's responses, if the infant has a hearing loss then a doctor or medical audiologist will inform the parents. Once the parents are educated about their child's deafness and how to communicate, they will be referred to a local hearing center at the nearest hospital for further information and testing. At the hearing center, the parents will obtain more information from a pediatrician about their child's health, an ophthalmologist for potential eye diseases associated with hearing loss, and an audiologist about the various technical aids. If necessary, the parents will meet with a psychologist to help cope with their child's hearing loss. In the next paragraphs, details regarding each type of referral will be discussed.

The pediatrician will refer the deaf child for genetic testing of Connexin 26 and CMV infection. Connexin 26 is a sophisticated molecular genetic research that has discovered over 30 genes tied to hearing loss in humans. It was found that 26 different

mutations affect the cochlea (Hall, 2006). CMV infection is an abbreviation from Cytomegalovirus, a herpetoviral infection that is usually transmitted in utero and affects the nervous system, brain system, hearing, and vision (Stach, 1997).

The ophthalmologist will check the infant's eyes for Usher Syndrome, which may affect hearing, balance, and vision. The various types of Usher Syndrome may result blindness and profound deafness. There is no treatment to cure it but educational programs, hearing aids, cochlear implants and/or American Sign Language may help people with Usher Syndrome adapt to their environment (National Institute on Deafness and Other Communication Disorders, 2008).

The audiologist will meet with the parents and discuss the level of hearing loss of the child by reviewing his/her audiogram. The audiologist will then discuss technical aids such as hearing aids, FM system, or cochlear implants. The devices are at no cost to the parents and are covered by the health care system. Once the parents are informed about the choices, the process for receiving a technical aid begins. Parents who choose hearing aids will be given brochures and books about how it works. Parents who choose cochlear implants will be referred to the cochlear implant team.

Question 4 and summary:

Question 4: Who is on the medical team that was introduced to the patient receiving a hearing device?

Representative A:
Doctor, audiologist, social worker, psychologist and pedagog (children).

Representative B:
Physician, audiologist, at times also a speech pathologist, CI engineer.

Representative C:

When needing a CI parents meet a team in the CI clinic; doctor, audiologist, special teacher, speech pathologist, psychologist, etc.

Representative D:

Medical audiologist (also ENT surgeon), audiologic technician for children, engineer, teacher for the deaf, speech therapist (for some children), teacher of signed language (some children) and counselor.

Summary of responses for Question 4:

Based on the responses for question 4, the common members on the medical team consist of a doctor, medical audiologist, psychologist, speech pathologist, and teacher of the deaf. According to *The Parents' Guide to Cochlear Implants* by Patricia M. Chute and Mary Ellen Nevins, a doctor, audiologist, speech/language pathologists, psychologist/counselor and sometimes a teacher of the deaf staff the cochlear implant program (2002). Huw R. Cooper and Louise C. Craddock mentioned a similar list in *Cochlear Implants: A Practical Guide* (2006). Representative B stated that a CI engineer was part of the medical team. It is unknown from question 4 if the medical team suggests hearing aids or cochlear implants for the patient because the doctor or the audiologist usually start the dialogue as to which devices are best for the child and then refer to a particular staff or hearing center. This leads to question 5 for further inquiry. Interestingly, there was no mention of a deaf advocate on the team or any organizations that encourage the use of sign language. It is also not clear if the teacher of the deaf or sign language teacher may be a deaf person. The only organization mentioned was Barnplantorna.

Question 5 and 6 with a summary:

Question 5: What suggestions are made to the patient on the type of hearing devices?

Representative A:

The audiologist suggests the hearing aid that is best for the patient, depending on the level of hearing loss.

Representative B:

Hearing aids and if these are insufficient, a CI will be offered.

Representative C:

Depends on hearing loss. If the child is supposed not to develop spoken language with "only" hearing aids then discussion about CI is beginning.

Swedish Health care system pays for hearing aids/CI also there is no cost for parents. All children that are born and in the need of CI receive it!

Representative D:

Bilateral hearing aids (BTE), FM systems when appropriate. All these devices are free to the child.

Question 6: Which hearing devices would be recommended and why?

Responses from Question 6 were eliminated because the responses were left blank, referred to question 5, or have similar responses to question 5. Question 6 failed to clarify that the researcher wanted to know the models that the audiologist recommends.

Summary of responses for Question 5:

From the responses in Question 5, the audiologist suggests the technical aid which is best for the patient depending on the level of hearing loss. Bilateral hearing aids (BTE) will be suggested, FM system when appropriate, then cochlear implant if the previous two are insufficient. The child is supposed to develop spoken language with the technical aids so, whichever is the best for the child to achieve this goal. If parents agreed, the child will receive it. No matter which device is chosen, it is covered by the Swedish health care system at no cost to the parents.

Question 7 and summary:

Question 7: What is the standard procedure for a person to receive a cochlear implant?

Representative A:

When the patient's diagnosis is set, the patient is sent to the cochlea implant team. A new investigation is made to confirm the diagnosis. Patients spend 6-8 h at the cochlea implant team taking new hearing tests, talking to other patients, speaking to the social worker and the children meet a speech- and language therapist.

Representative B:

1- is it necessary? (assessment of best ear)
2- are the parents interested?
3- is it possible? (MR, CT, at times promontorial stimulation)
4- is it safe? (syndromes, ECG, anaesthesiologist, vaccinations)
5- parent's decision after information on chances, goals, risks involved, procedures
6- surgery
7- connection of processor four weeks later, guided mainly by NRT, sometimes by visual observations of responses, or the stapedial reflex during surgery.

Please note that 35% of patients have additional handicaps (autism, vision, malformations, syndromes).

Representative C:

Medical tests etc. Standard procedure that is pretty much the same all over the world. Child must be old enough to cope with anesthetic. Child must have a weight over 8 kilo because of that.

Representative D:

Referral to the regional cochlear implant team for investigation. ABR, ECoG in general anaesthesia, meeting medical audiologist (information about CI, ENT status including vestibular testing), audiological technician (psychoacoustic testing including free field tresholds with hearing aids), speech therapist, teacher of the deaf (often meeting a family with a CI child) and counsellor. MRT and CT scans (often in general anaesthesia). Meeting with the ENT surgeon and engineer.

Summary of responses for Question 7:

The standard procedure in Sweden is similar to the medical practices around the world. The difference is that the devices are at no cost to the parents so they will choose

which is best for their child. The choice may be the hearing aid or cochlear implant. Although in question 9 where doctors and the audiologist mention bilingualism to parents and the use of both Swedish Sign Language and spoken Swedish when communicating to a deaf child, it is common that the parents will lean toward a device that will help bring the child to become more "normal" or a "hearing person" along with the ability to communicate in spoken language. This decision was made without an advocate for Swedish Sign Language on the team, especially a deaf representative from the deaf community. Once the diagnosis of a severe to profound hearing loss is made, hearing aids are tried. If there is a lack of benefit from hearing aids, the patient will be sent to the cochlear implant team if his / her choice was to receive a cochlear implant. The doctor will assess both ears and determine if the child can undergo surgery without complications or medical risks. Before surgery, the child goes through another series of tests similar to the Universal Newborn Hearing Screening procedure to make sure that nothing gets overlooked. The emphasis is on the physiology of the child and the level of hearing loss for appropriate technical aids. The Magnetic Resonance Tomography (MRT) and CAT scanning (CT) use noninvasive x-ray equipment to scan the child's head for the status of the cochlea and for the placement of the internal component of the cochlear implant device. The doctor will discuss the medical risks and process that the child will go through to receive the implant. If necessary, the parents and or child will meet with the psychologist to learn to cope through this transition of surgery and post-implant. The child will undergo surgery to receive the cochlear implant and then a few weeks later after healing will be fit with the external component of the cochlear implant device. The child will go through speech and language training with the speech and

language therapist. Both books, *The Parent's Guide to Cochlear Implants* and *Cochlear Implants: A Practical Guide,* are good references to learn in detail about the common medical practice for receiving a cochlear implant.

Question 8 and summary:

Question 8: After the patient receives a cochlear implant, what training is recommended?

Representative A:

For most adults no specific training is recommended. For children specific speech- and language training is recommended. The training is individual, depending on the child's ability. Deaf-born children need a lot of support to acquire age-equivalent, spoken language development.

Representative B:

The same as with hearing aid training, only with a CI. Focus on hearing and talking. An individual training programme is made, including frequent councelling at home and in groups (however, not as frequent as described in the AVT programme). Specialised day-care centres can be very helpful, but there are some day-care centres who focus on signing even after implantation, leading to decreased auditory benefit of the CI since the children can be tired and less perceptive for auditory training when they come home after the day.

Representative C:

That is different according to the child's need but I am sorry to say that even though we have a standard procedure with medical tests before surgery we don't have that developed training program. It depends on where the family lives and the attitudes toward CI still! In some parts parents is recommended to go for bilingualism.

Representative D:

Regular meeting with engineer/audiological technician, speech therapist, teacher for the deaf. Will be followed by the medical audiologist. Spoken language is of course heavily stressed, but we also encourage signed language.

Summary of responses for Question 8:

Based on these responses to question 8, there is not a developed standard training for cochlear implant in Sweden. Each individual is tailored to his or her own training

program depending on his or her needs and ability. In the United States, Auditory-Verbal Therapy (AVT) is gaining popularity as a training program used to facilitate the acquisition of spoken language through a one-on-one guide where the parents are taught how to listen to their newborn or child and encourage talking and hearing (Alexander Graham Bell Academy for Listening and Spoken Language, 2007). In Sweden, some parents are referred to find a local day-care that specializes in sign language and spoken language development. Although some children with cochlear implants educated in the United States have the option to learn sign language, a bilingual policy is not in place.

Question 9 and summary:

Question 9: How are the parents of the patient informed about Swedish Sign Language?

Representative A:

All families get information about Swedish sign language or sign supported Swedish. Many families choose to take courses in Swedish sign language or sign supported Swedish, but not all families.

Representative B:

At diagnosis if hearing loss is severe or profound. We recommend its use up til CI implantation, but after that focus is recommended on hearing and talking. In case of a very favourable result of bilateral implantation, patients/parents sometimes use sign language very seldom, in spite of our recommendations.

Representative C:

All parents have an option through health care system to learn sign language. Nowadays not all parents fulfill that learning program anymore since the children gets bilateral CI under the age of one the result in developing spoken language is very good so parents drop the sign language. It also depends in what kind of preschool and school setting the child attends. Mainstreamed children (increasing amount of CI children) parents leave the sign language. Children in deaf school parents have a greater focus of sign language and bilingualism. (spoken language + sign language)

Representative D:

They are informed about signed language by the medical audiologist, teacher of the deaf and speech pathologist. We have teachers of signed language in the team, organising classes in signed language for children, parents and relatives.

Summary of responses for Question 9:

Families or parents are informed about the Swedish Sign Language courses through the teacher of the deaf, medical audiologist, and/or speech pathologist. Sign language courses are offered through the Sign Language Training for Parents program, known as TUFF in Swedish, which is given by the National Agency for Special Needs Education and Schools (formerly the Swedish Institute for Special Needs Education). The TUFF program entitled parents up to 240 hours of sign language instructions at no charge since the Swedish government subsidized this program (Sveriges Dövas Riksförbund, 2007a; Angerby, 2005). It was noted by some representatives in the questionnaires that not all parents or families follow through the TUFF program because cochlear implants developed the child's spoken language very well. The parents saw no need to continue learning sign language.

Question 10 and summary:

Question 10: What roles did the parents and the Swedish National Association of the Deaf have in the cochlear implant process?

Representative A:

I do not really understand this question, but the parents are very important in the cochlear implant process, of course. The Swedish National Association of the Deaf is not directly involved in the process.

Representative B:

In the eighties, parents were sometimes given conflicting information from surgeons and the Association of the Deaf. Doctors wanted to operate early, whereas the Association recommended no surgery at all. As a compromise, it was

advised that children first learned to sign, and then received a CI. This did not work. Now, the age of surgery is low and the results are good. I am not aware that the Swedish National Association of the Deaf, or any other organisation of the deaf or hard of hearing, have any role at all in the parent's decision process. An exception is Barnplantorna, the Swedish association for parents and children with CI, representing a strong support for implant surgery.

Representative C:

Parents are very positive towards the CI clinic. Over 80% of the parents to cochlear implanted are members of BARNPLANTORNA (the only organization that represent CI children and their parents) BARNPLANTORNA have a global cooperationship with other CI organizations, cooperationship with the CI clinics, the manufacturer both nationally and globally.

The Swedish Association for the Deaf is of many parents to CI children still regarded as negative towards CI especially if the parents choose mainstream for their child and don't involve themselves in bilingualism for their child.

Representative D

There are several national organisations for the deaf and hard of hearing. Sometimes the families are members of more than one organisation. Most families with children using CI are members of the national organisation "Barnplantorna", an organisation targeted on these families. There is quite a close cooperation between this organisation and the medical CI teams, e.g. courses and meetings. Of course, the parents make the ultimate decision whether to accept a cochlear implant or not. The medical team and the organisations have to give the family information and facts making it possible to do an informed decision, not to make the decision.

Summary of responses for Question 10:

The question asked if the medical practices in Sweden for the deaf include the Swedish National Association of the Deaf (SDR) or a deaf person on the medical team. According to the European Union of the Deaf report to the Council of Europe, it was mentioned that none of the medical teams includes a deaf person (Preisler, 2001). All representatives from this questionnaire have responded that SDR is neither directly involved in the process nor part of the medical team. The only exception is Barnplantorna because this is a support organization for parents of children with cochlear implants. It

was interesting to learn from Representative B that during the eighties, doctors and SDR gave people conflicting information about cochlear implants. Does this conflicting information in the eighties between the doctors and SDR to the patients cause an exclusion of SDR from the process? Did the health care system feel that SDR has no medical expertise on the technical aids? Or perhaps SDR chose not to be involved in the process. In addition, does the hospital feel that the teacher of the deaf is sufficient enough to educate the parents about bilingualism and deaf culture rather than a representative from SDR would be? Do the written materials include deaf culture and identity or just how technical aids work and bilingualism? Additionally, representative B said that doctors advised the family that the deaf child learn sign language and then receive the cochlear implant, however, it did not work. The researcher wonders if it was just an opinion of the representative that "it did not work" or that Representative B noticed the family did not follow through with learning Swedish Sign Language and used spoken Swedish instead once their child learned to hear. Bagga-Gupta and Domfors wrote in their *Pedagogical Issues in Swedish Deaf Education* paper that:

> A very small minority of Deaf students (about 5%-10%) comes from homes where SSL has been a full-fledged functioning language throughout their childhood. The principally hearing caregivers of the overwhelming majority of Deaf children go through a chain of language courses and frequently consider themselves to be incompetent in SSL – a language that is perceived as their "second language" through their active parenting years. (2003, p. 76).

The researcher thought that parents may be struggling to use both spoken Swedish and SSL with their deaf child because they are learning a new language which requires

commitment and patience. By having a cochlear implant, it potentially makes the parents' life easier if their deaf child can hear and speak well. Representative D mentioned that parents make the ultimate decision to proceed with a cochlear implantation or not. The medical team and organizations provide the family with facts and information on deafness and hearing devices so that parents can make an informed decision. Further studies could explore how much the family knows about deafness and how much do they communicate with their deaf child? It would be interesting to explore in future studies the perspectives of doctors toward the bilingual model and cochlear implants, as well as the family that receives information on deafness.

Follow-up question and summary:

Does the CI-Team give brochures or materials to the parents about their child's deafness?

Although the researcher has more questions about the process and the deaf community in Sweden, the inquiry about the written materials was asked as a follow-up to this thesis research. Two representatives were sent this question by email and both gave similar answers, that the hospital gave out written materials to the parents about their deaf child. One representative summarized in a response:

> *"The written material is given to the families according to their individual needs. If they get hearing aids they will have a brochure for the child explaining what they will experience during the hearing aid fitting… The parents are given a book on hearing and hearing aids (När ljudet blir svagare – om hörsel och hörapparater) written by two Danish collegues, Claus Elberling and Kirsten Worsöe, translated to Swedish. If a child is candidate for a cochlear implant, the child will get a book explaining what a cochlear implant means. It is written in collaboration with the CI team in Huddinge, Stockholm, a writer and an illustrator of children's books and a Swedish national foundation for hard of hearing children (Ulla Ståhlberg. Pelle och CI-apparaten – en barnbok om cochleaimplantat). The parents are given a brochure produced by Cochlear Nordic AB (Föräldrainformation om cochleaimplantat för*

> *hörselskadade barn). They are also given a DVD produced by the CI team in Gothenburg in collaboration with the national organisation for children with cochlear implants, Barnplantorna (Cochleaimplantat – att återskapa ett sinne). The teacher for the deaf and our teachers of signed language give oral information (besides classes) on signed language and on different alternatives concerning educational settings. They also often arrange meetings with families of children who already have received a cochlear implant."*

This response summarized the names of published materials given out to the parents and those who educate the parents on hearing devices. It showed that Barnplantorna gave out an educational DVD about the organization and cochlear implants. The teacher of the deaf gave oral information about the sign language courses and alternatives to an educational setting. It was assumed by the researcher that information might be given in limited amounts so that parents would not be overwhelmed after meeting with different medical professionals.

Summary of Objective 1:

All newborns in Sweden go through the Universal Neonatal Hearing Screening process. Once the doctor receives the results of the hearing tests, the doctor will inform the parents whether their newborn is deaf or hearing. If the newborn is found to be deaf, then the parents will be referred to the audiologist and medical team consisting of a doctor, medical audiologist, psychologist, speech pathologist, and teacher of the deaf. Parents will be informed where to take sign language classes and the types of hearing assistive devices available for their child. If a cochlear implant is the choice for the deaf child, then the process for cochlear implantation begins. It is encouraged for parents to learn sign language and speech training for the child using the hearing assistive device. Following up with questions posed at the beginning of the paper: *Are the criteria and*

process for receiving cochlear implants any different from the United States? The process for receiving the cochlear implant is similar to the United States but the earliest age for receiving a cochlear implant was 6 months or older in Europe while the Food and Drug Administration in the United States approved the implants for children as young as 12 months (St. James, 2010; Belzner & Seal, 2009). In some cases, the family is encouraged to learn sign language prior to the deaf child receiving the cochlear implant. *How does the medical team support the bilingualism policy through various types of hearing assistive devices?* As can be seen from the responses in the questionnaire, the message promoting bilingualism varies between the experts that the parents interact with. Some experts will encourage Swedish Sign Language; while some will focus on the technology available.

It was interesting to learn from the responses of the different representatives their perspectives on bilingualism and what they noticed in deaf children receiving cochlear implants. There are two different views that exist in Sweden: the medical perspective and the community perspective. The medical perspective toward a deaf person is to find the best solution to restore hearing loss as close to normal hearing as possible through hearing assistive technology or surgery. The deaf community perspective toward a deaf person is that no matter what medical solution is available to restore the hearing loss, the deaf person will always have a 'deaf' identity that belongs to the deaf community and sign language is a natural language, which is a civil right and should be protected. The bilingual policy in Sweden clearly states that deaf children have the right to learn and use both Swedish Sign Language and spoken Swedish.

There is a repetition of a similar message throughout the responses from the questionnaire that parents and the families do not follow through with the bilingual policy. Although medical staff stated that they encouraged the use of sign language and the development of spoken language with the best technology available, the parents and families did not follow through with the bilingual policy, which is learning Swedish sign language outside of the hospital. In this researcher's opinion evaluating three different environments such as schools, hospitals, and organizations, the bilingual policy can be strengthened.

In schools, encouraging people to use the Swedish Sign Language in the classroom environment could strengthen the bilingual policy. It was mentioned by Representative C that application of the bilingual policy depends on which school the deaf child attends because the school environment influences the type of communication that exists between the family and the deaf child. If the deaf child attends a school where bilingualism is regularly used, the parents are more likely to maintain the use of sign language than those deaf children who are attending a school where spoken language is predominately the language of instruction. In addition, when deaf children received cochlear implants at a younger age, the parents would focus on using the spoken language rather than maintaining bilingual communication. If the parents see that the bilingual approach in *all* children has a positive use in communication then they are more likely to be encouraged to take courses and use sign language with their children regardless of the child's hearing status or age of cochlear implant surgery. Parents and families have been offered the opportunity to take 240 hours of sign language courses, which are covered by the government at no cost (Sveriges Dövas Riksförbund, 2007a).

One of the researcher's ideas is to offer the Swedish families with a deaf child a tax credit for completing 240 hours of sign language courses. The tax credit promotes sign language use and encourages bilingual communication within the family. The bilingual policy could be strengthened further by encouraging teachers at any of the schools that the deaf child attends to incorporate sign language into their interaction and instructions. Since it is not possible for all of the teachers in compulsory education to learn sign language, it could be encouraged at the preschool level as an early intervention approach strategy along with the cochlear implant. The use of sign language by teachers in preschool does not only benefit deaf children but also t hearing children who have not begun speaking yet.

As mentioned earlier in this document, the doctor on the medical team is among the first, other than the audiologist, to inform the parents of the status of their child's hearing loss and make a recommendation as to what they think is best for the deaf child. The bilingual policy protects the rights of deaf children to learn both Swedish Sign Language and spoken Swedish. There are two factors that impact or weaken the bilingual policy in the hospital environment. The first factor is having adequate time for the parents to master Swedish Sign Language prior to cochlear implant surgery for their deaf child. Having a cochlear implant as early as possible is critical for the development of the spoken language and the earliest cochlear implant surgery documented is at 6 months (St. James, 2010; Belzner & Seal, 2009).

The first factor is that parents who received 240 hours of free Swedish Sign Language courses may feel pressured to learn quickly, perhaps by the time their child is 6 months of age. This must occur outside of their work and personal time prior to the

cochlear implant surgery. Instead, many parents would find it easier or less stressful to focus on the development of the spoken language and use sign language less and less over time once the deaf child has developed stable communication with the parents.

Secondly, the researcher believes that the medical team at the hospital is biased in the information they provide to parents, which further weakened the bilingual policy. Representative B said "in the eighties, parents were sometimes given conflicting information from the surgeons and the Association of the Deaf (SDR). Doctors wanted to operate early, whereas the Association (SDR) recommended no surgery at all. As a compromise, it was advised that children first learned to sign, and then received a CI. This did not work. Now, the age of surgery is low and the results are good." In a report by the Council of Europe, it was noted that there has not been a deaf representative on any of the medical teams (Preisler, 2001). Based on the questionnaire responses, Barnplantorna, which supports hearing assistive technologies, is the only organization that supports the medical team and interacts with the parents about cochlear implants and the surgical process. It was also noted that Sveriges Dövas Riksförbund (SDR), an organization that supports Swedish Sign Language, has been silent about participating with the medical team in informing the parents of the communication choices that the deaf child has. SDR and Barnplantorna represent two different communication methods for the deaf. Barnplantorna fits the medical perspective that the hospital has maintained, which is to make any person "whole" with their body functions as "normal" as possible through hearing assistive technologies or surgery. SDR fits in the deaf community perspective that a deaf person does not need to be fixed with the best technologies available but needs to be educated in the language that is natural for a deaf person, which

is Swedish Sign Language. Representative C stated that over 80% of the parents of deaf children with cochlear implants are members of Barnplantorna. Representative C also stated that many parents have been given negative attitudes by SDR if they don't involve themselves in bilingualism for their deaf child. The researcher recommends eliminating the involvement of any organizations in the process if only one has a direct influence. If more than one organization were invited and have presented their perspectives to the parents about options for the deaf child then this would give the parents a balanced perspective in making their decisions with the medical team. This means Barnplantorna should not serve on the medical team alone. Furthermore, it is also recommended that the medical team provide their own written publication about the bilingual policy and the communication methods available. Barnplantorna and SDR can provide their own brochures, in addition to the hospital's publication, as long it encourages a bilingual policy.

The growing number of cochlear implant users in Sweden will have an impact on the future of bilingual policy and deaf identity in the deaf community, especially advocating organizations such as Barnplantorna and SDR. Many deaf children are receiving cochlear implants and as they get older, they will blend in with the rest of the society. There will be an identity struggle to belong to a certain group that shares the similar experience. Barnplantorna has been providing support to these new cochlear implant users. SDR acknowledges this growth of cochlear implant users and even mentioned it in their 2007 annual report by stating that they are not against cochlear implants because with or without it, the person is still deaf. SDR values sign language as a natural right for the deaf person. If SDR does not embrace and welcome these new

generations of cochlear implant users by changing its defensive attitude, then their current memberships will be affected. SDR need to re-strategize how to encourage parents to continue using the Swedish Sign Language among the growing number of cochlear implant children and increase the use of Swedish Sign Language in the school environment.

In closing, after reviewing the impact of cochlear implants in schools, hospitals, and advocating organizations, the bilingual policy could be strengthened by changing the attitudes toward the parents to encourage more Swedish Sign Language use with their deaf children. In preschools, teachers could incorporate Swedish Sign Language in their instructions toward both deaf and hearing children. On the medical team, the information presented to the parents could be less biased if advocating organizations were limited to outside of the hospital procedure and be allowed to make connections with the parents through brochures and publications that encourage bilingual policy. Further research studies and publications could show the parents and the people in Sweden the impact of bilingual policy toward the new generation of deaf children. It may have a positive impact to preserve the use of Swedish Sign Language regardless of technology or perhaps less beneficial with cochlear implantation at a younger age, which supports spoken language development.

4.2 Findings for Objective 2

Objective 2 is "*Gather existing policy statements on cochlear implants from major community organizations serving deaf people.*"

Five organizations/agencies were chosen to participate in this section of the questionnaire. All organizations and agencies except one responded to the researcher's inquiry about the policy statement. The questionnaire results were either filled out, partially answered in the email, left blank, or declined to participate because the organization/agency does not have a policy statement on cochlear implant. Only two organizations/agencies have a policy statement on cochlear implants while the remaining three have no policy statements on cochlear implants. Those with policy statements on cochlear implants can be also found on its website. For this section, the English translation will be shown and the original statement in Swedish is available in Appendix H.

Representatives:

- Barnplantorna- *the National Association for Children with cochlear implant in Sweden*.
- Equality Ombudsman (previously Handikappombudsmannen) (HO)
- Riksförbundet för döva, hörselskadade och språkstörda barn (DHB)- *the National Association for the deaf, hearing impaired and language impaired children*.
- Skolverket- *the Swedish National Agency for Education.*
- Sveriges Dövas Riksförbund (SDR)- *The Swedish National Association of the Deaf.*

Instead of sharing the results because of random responses, a copy of the organization/agency's mission statements will be listed along with any public policy statement on cochlear implant that is found on the website.

Does the organization/agency have a policy statement on cochlear implant?

- Barnplantorna- Yes, see mission statement section
- DHB- No, there is none
- Equality Ombudsman- No, there is none
- Skolverket- No, there is none
- SDR- Yes, see mission statement section

Mission statements:

The objectives of Barnplantorna:

The Barnplantorna's mission statement was taken from Barnplantorna's 2008 annual report:

"***The purposes of Barnplantorna:***

- *To protect children and young people's interests in a highly changing world on the basis focus on each individual's opportunities, challenges and visions. Children with various hearing aids.*
- *To arrange meetings for social fellowship for its members.*
- *To assist families in touch with other families, create networking for members, to parents to be able to take an active part in its child development to full self-confidence and self-sufficiency.*
- *To inform members of CI and the technical developments in cochlear implant field. This is achieved through a broad cooperation with manufacturers both nationally and internationally.*
- *To work together with manufacturers of various aids to CI and hearing aids and manufacturers of Baha and representatives of hearing aid industry.*
- *To inform members of opportunities in different preschool / school selection and support the individual family in its decision on preschool / school selection independent of elections.*
- *Informing and raising awareness of our children to professionals habilitation / preschool / school*
- *Informing people about the essence of the children's hearing is important for language development (speaking, writing) and the development of age-appropriate vocabulary.*
- *To engage a broad interest in political work in order to safeguard members' interests in dealings with authorities, nurseries, schools, individual professional and habilitation.*

- *Following research in the deaf / hearing area by contacts with various research network in Sweden but also globally.*
- *To inform the general public about the cochlear implant children (as a relatively new hearing aids) to ensure that all children with different hearing aids -- through understanding in the community - receives optimal conditions in the society we all want to be an active part.*
- *To conduct a comprehensive training courses for parents as well as professionals in rehabilitation services, preschool and school.*" (Barnplantorna, 2008a)

Summary of Barnplantorna's mission statement:

In 1995, Barnplantorna was originally a support organization for children with cochlear implants. In 2007, it became an advocacy organization for middle ear implants, cochlear implants, and hearing aids. The organization's mission statement has a language change to include middle ear implants and hearing aids and this was noticed in the 2007 annual report when comparing all reports from 2005 to 2008. The change in the organization's mission statement and structure seemed to be more collective and centralized on information about technical devices than it was before 2007. It mentioned in its reports and on the website a list of manufacturers and specific devices that are distributed to Sweden. This helpful information was not available at the time of research in 2007. It appears to be that Barnplantorna considers cochlear implants as an advanced form of hearing aids and promotes it for the child's language development, more specifically toward the spoken language. Barnplantorna continues to support bilingualism of both Swedish Sign Language and spoken Swedish; however, it was not mentioned in its mission statement. Barnplantorna only mentioned the use of Swedish Sign Language as part of deaf culture at another part of its website. Based on the public information on the website, Barnplantorna supports the use of hearing assistive technology, mainly the cochlear implants in deaf children. Also on the website, Barnplantorna briefly mentioned

to parents about Swedish Sign Language and the fact that it is part of deaf culture (Barnplantorna, 2009c).

The objectives of the Swedish National Association for Deaf, Hearing-Impaired and Language-Impaired children- DHB:

The vision statement was found on the DHB's website and it is available in English:

> "***Our aims and vision***
> *Our aims are that children who are deaf, hearing impaired or language-impaired shall have all possibilities to participate on equal terms in our society. Important questions for DHB are:*
> *The quality of the education for our children*
> *Education in sign language for our families and relatives*
> *Economic questions for our member families*"

Summary of DHB's objectives:

DHB advocates for children who are deaf, hearing impaired or language-impaired by protecting their rights to a high quality of education and bilingualism (more emphasis is on sign language). DHB carefully observes the Swedish government and authorities for anything that may threaten access to quality education and sign language by identifying important issues in the education system, schools, and social environment that the children of DHB shares. The information retrieved from DHB does not show any specific policy statement on cochlear implant.

The objectives of the Equality Ombudsman:

The Equality Ombudsman's mission statement was taken from its website under "About DO":

> **"What does DO do?**
> DO's mission is to combat discrimination on grounds of gender, transgender identity or expression, ethnicity, religion or other belief, disability, sexual orientation or age. But DO can only intervene if there are issues related to working life, colleges and universities, school and school-age childcare and some

other areas of society. Protection against discrimination is also a bit different depending on the ground of discrimination involved."

Summary of the Equality Ombudsman's objectives:

Based on the public information from the Equality Ombudsman's website, there is no policy statement on cochlear implants. The former Disability Ombudsman ceased to be a public authority and became part of the Equality Ombudsman on January 1, 2009. The current Equality Ombudsman no longer contains the mission statement or publications of the previous Disability Ombudsman (thus "DO").

The objectives of Skolverket:

The objectives of Skolverket, the National Agency for Education, can be found on its website under "About us":

"*The Swedish National Agency for Education*

The Swedish National Agency for Education is the central administrative authority for the Swedish public school system for children, young people and adults, as well as for preschool activities and child care for school children. The Agency also has responsibility for coordinating national initiatives for pupils with disabilities, environmental issues and issues relating to pupils who have just arrived in Sweden.

The tasks and role of the Agency
Government and Parliament specify goals and guidelines for preschool and school through the Education Act, curricula etc. The task of the Agency is to work actively for the achievement of these goals. The Agency steers, supports, follows up and evaluates the work of municipalities and schools with the purpose of improving quality and the result of activities to ensure that all pupils have access to equal education.

The Agency´s contribution to improved quality
National goals and governing documents

- *Establish frameworks and guidelines for how the education is to be conducted*

and assessed using goal documents, syllabuses, tests, grading criteria and general guidelines.

- *Be responsible for the national testing system. Together with universities and colleges The Agency develops national tests and diagnostic material in order to ensure equality in the assessment of pupils.*
- *With financial help the Agency is also responsible for distributing and evaluating government grants for the achievement of goal fulfilment and for guaranteeing quality in the different activities.*

National school development

- *Support preschools and schools in their development. The support provided shall be given national priority. The support may be provided for general development needs identified as shortcomings or problems in national or international surveys in areas such as mathematics, languages and reading and writing*
- *Skill development for school staff is an essential element in our new organisation. The Agency is responsible for the national school head training and for professional development for teachers.*
- *Disseminate information about research and experience that are of significance for school heads and teachers.*

Evaluation

- *Participating in international evaluations in order to gain more in-depth knowledge on comparable education systems and on how other countries have dealt with areas similar to those needing improvement in the Swedish education system.*
- *Focusing on, by way of national evaluations, areas where development is needed at the national level, as well as providing the underlying basis for this development, e.g., to help school principals and supervisors in their efforts to lead and rejuvenate activities at the local level.*

Follow-up

- *Collecting, analyzing and publishing relevant statistics in this sector. We follow up the prerequisites of the different activities, how the activities are conducted and how the results develop, by the continual collection of data from the municipalities. This allows comparison of different organizers and activities.*

  A director general heads the Agency and, in order to improve the Agency´s quality and reinforce its establishment in society, a council is appointed by the government."

Summary of Skolverket's objectives:

The goal of this agency is to evaluate the quality of compulsory education in all schools making sure that all pupils have equal access follow up with statistics and reports. Skolverket covers all municipalities from preschool to college and including vocational training schools (Skolverket, 2009b). Skolverket does not have any public statement on cochlear implants.

The objectives of SDR:

SDR has a public brochure with vision statements available in both English and Swedish:

> "*Vision for SDR*
> - *In Sweden we live in a society where signing deaf people throughout our lives have the right to express ourselves in our own language –Sign Language.*
> - *In this society we who are deaf can communicate in sign language and receive knowledge and information in sign language.*
> - *Nobody questions our rights and the political decisions which affect people in general do not exclude us who are deaf.*
> - *We who are deaf have full access to the services of society, information, child care, education, social services, working life, culture and club activities. The rapid development in the field of information technology does not exclude us. We are included as a natural part of the development.*
> - *We who are deaf senior citizens have, as well as all senior citizens, an adequate care for the elderly. That, for us, also implies a functioning communication in sign language.*
> - *We who are deaf live in and participate fully on the different levels of society, on our own conditions, with our own language – Sign Language.*"

Summary of SDR's objectives:

The vision statement does not state anything about cochlear implants; however, this can be clarified in the Swedish version of the website. SDR expressed strong value about preserving sign language and has its own opinions about cochlear implants throughout some of its publications. One particular section of the website on cochlear

implant was retrieved:

> "***Children need sign language***
> ***Children with cochlear implants need to sign - as well!***
> *There are those who believe that dövrörelsen in Sweden are against cochlear implants (CI), and therefore against the deaf children receive help with their hearing.*
>
> *This is wrong. We are not against CI or that deaf children receive help with their hearing. On the contrary, CI is a sophisticated hearing aid that works well for many deaf children. But we will react against the doctors and other makes CI as a technological marvel that makes the child hearing and therefore do not need sign language.* ***The child is not hearing, but hearing loss, and need sign language for all situations in life when their hearing in spite of CI is not sufficient.*** *If and when CI is removed the person is deaf and rely on communication in sign language…*"

Regardless of the hearing devices that a child uses, SDR strongly supports the use of sign language throughout the deaf or hard of hearing person's life. It will stand by its vision to protect that right. SDR is not against CI or hearing aids because with or without it, the person is still deaf. SDR has emphasized this position statement throughout some of its publications.

Summary of Objective 2:

Of the five groups that responded to the questionnaire, only two organizations have a policy statement on cochlear implants. Barnplantorna promotes the use of hearing assistive devices and encourages cochlear implants. SDR advocates the use of Swedish Sign Language and is not against the use of cochlear implant or any other hearing assistive devices because without them, the people are still deaf. SDR strongly support the use of Swedish Sign Language as a necessity in communication. DHB, Skolverket, and the Equality Ombudsman all do not have any policy statement on cochlear implants because their mission focuses on education and equal access for people with disabilities.

It was noticed that Barnplantorna did not mention bilingualism and the use of Swedish Sign Language in its mission statement but was briefly mentioned as part of deaf culture in other part of its website.

In addition to the summary, *do some major organizations support cochlear implant technology?* Barnplantorna appears to be one that is advocating for the use of cochlear implants while the others have no policy statement about it except SDR, which is not against it. *Does the policy statement from each major organization support bilingualism policy in Sweden?* There is no clear policy statement supporting bilingualism. There are organizations that advocate the use of Swedish Sign Language but none of the organizations have placed spoken Swedish in the same statement to promote bilingualism.

4.3 Findings for Objective 3

The third inquiry of this research is to "*collect historical and current statistical data of the deaf population who have cochlear implants or hearing aids in compulsory education including special schools (first grade to ninth grade).*" There are several sources that provide statistics on student population, regular schools, cochlear implant users, and deaf people. The researcher will discuss the bigger picture of the overall population and then briefly discuss compulsory education and if there is any impact from the emergence of cochlear implant technology.

<u>Organizations and agencies with statistics:</u>

- Skolverket- *Swedish National Agency for Education*
- Specialpedagogiska skolmyndigheten- *Swedish National Agency for Special School*

- Statistics Sweden Agency (SCB)
- European Association of Cochlear Implant Users (Euro-CIU)
- Barnplantorna
- The Swedish National Association of the Deaf (SDR)
- The Swedish Association of Hard of Hearing People (HRF)

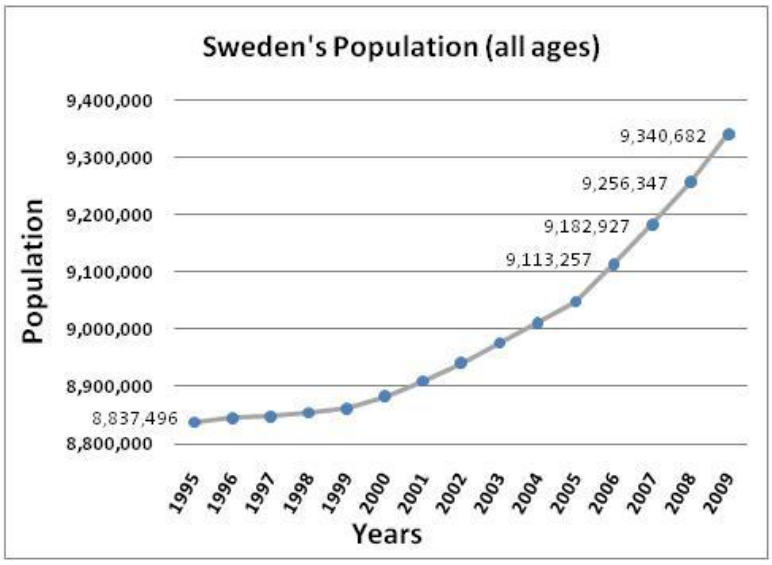
The Statistics Sweden Agency is responsible for publishing official statistics for public information, planning and research purposes. Many of its statistics are used by many organizations and agencies including the Swedish National Agency for Education (Skolverket). The researcher contacted the Statistics Sweden Agency, Skolverket, and the Swedish National Agency for Special Schools for specific numbers of cochlear implant users, hearing aid users, and deaf students in compulsory education. This type of statistic for all schools is not available. However, there was some information available on special schools. The researcher followed up with other organizations and agencies for specific statistics and discovered that limited data was available. Barnplantorna provides the number of cochlear implants used by adults and children in Sweden and this is shared through its bi-annual report to the Euro-CIU. There are statistics available on the number of deaf people in Sweden through SDR and the number of hard of hearing people through HRF but not including deaf children in compulsory education. This section will discuss the trends in Sweden's population and how that affects the schools, in addition to the deaf statistics published by organizations and agencies.

Populations in Sweden

According to the Statistics Sweden Agency population statistics for 2009, there are 9,325,429 people living in Sweden. Data was retrieved from 1995 and 2009 to

demonstrate the population growth in Sweden. This data can be seen in Figure 4.1, *Sweden's Population (all ages) from 1995 to 2009*.

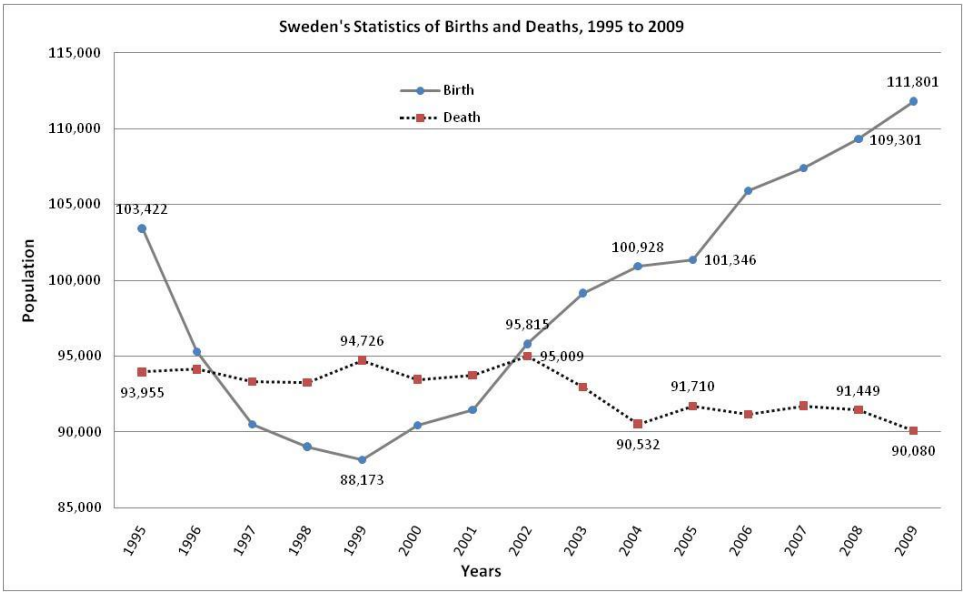
Figure 4.1
Sweden's population (all ages) from 1995 to 2009



**Taken from "Swedish Population (in one-year groups) 1860-2009" by the Statistics Sweden Agency (2009)*

This population growth is expected to increase over the next few years with Sweden's stable death rate and fluctuating birth rate. When looking at the statistics available online at the Statistics Sweden Agency website to further analyze the data into the 1950s, a trend for the birth rate was noticed. The trend for birth rate increases over a period of time and then decreases for a period of time before continuing the cycle of increasing and decreasing. From 1995 to 1999, the birth rate demonstrates a slow growth in population. From 1999 and toward 2009, the birth rate curve increases. See Figure 4.2 for the statistics of births and deaths from 1995 to 2009.

Figure 4.2
Sweden's statistics of births and deaths, 1995 to 2009

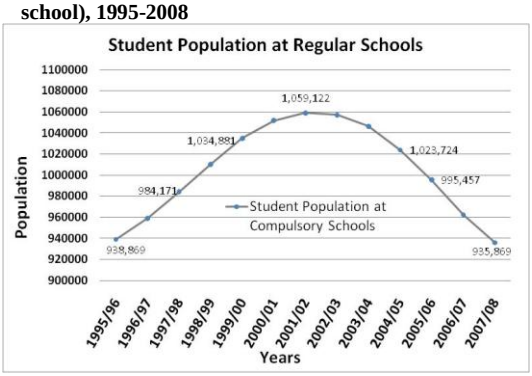


**Taken from "Population and Population Changes 1749-2009" by Statistics Sweden Agency, 2009*

The reason for showing these two sets of data for review was because statistics for regular schools and student population showed a decline in enrollment, which will be shown in Figures 4.3 and 4.4. Regular schools and special schools share the similar curve of declined enrollment. It could be assumed that cochlear implants in children have a significant impact on deaf students switching from special schools to regular schools, but it does not demonstrate that. As previously mentioned, Angerby reported that low birth rates and cochlear implants may have influenced the slight decrease in enrollment for special schools (2005). However, there are no national statistics supporting the decrease of enrollment in special schools because of cochlear implants. Looking at the population trends dating back to the 1800s, birth rates rise and fall almost every decade. Children do not enroll into regular school until they are six years of age or older. The birth rates from 1999 to 2009 show a trend that there will possibly be an increase in enrollment beyond 2009. It depends on individual deaf student needs for accommodations in special schools

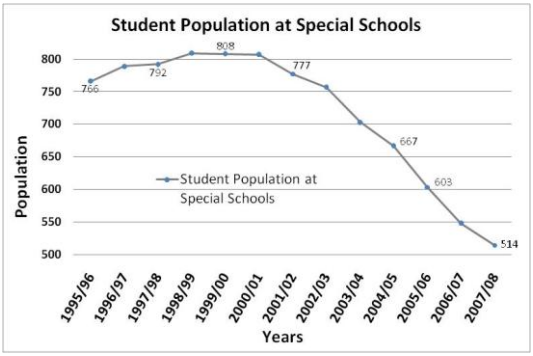
with or without cochlear implants. It cannot be assumed that cochlear implant has an impact on enrollment in special schools unless they have been implanted early and students do not need any other accommodations. With Universal Neonatal Hearing Screening, children will be given cochlear implants or other technical aids earlier and may be placed into regular schools more than special schools if they can learn without using special accommodations. Figure 4.3 shows the student population at regular schools from 1995 to 2008. The birth rate slowed the population growth until 1999. Showing the affect of birth rate's decline prior to 1999, the student population enrolled at regular schools increased slowly until 2001 and then declined afterward. It should be expected that the student population would increase its enrollment beyond 2009 based on the researcher's observation of a trend from population statistics of population changes dating from 1749-2008, published by the Statistics Sweden Agency.

Figure 4.3
Student population at regular schools (compulsory school), 1995-2008



**includes municipal schools, sami schools, independent schools, international schools, and national boarding schools*

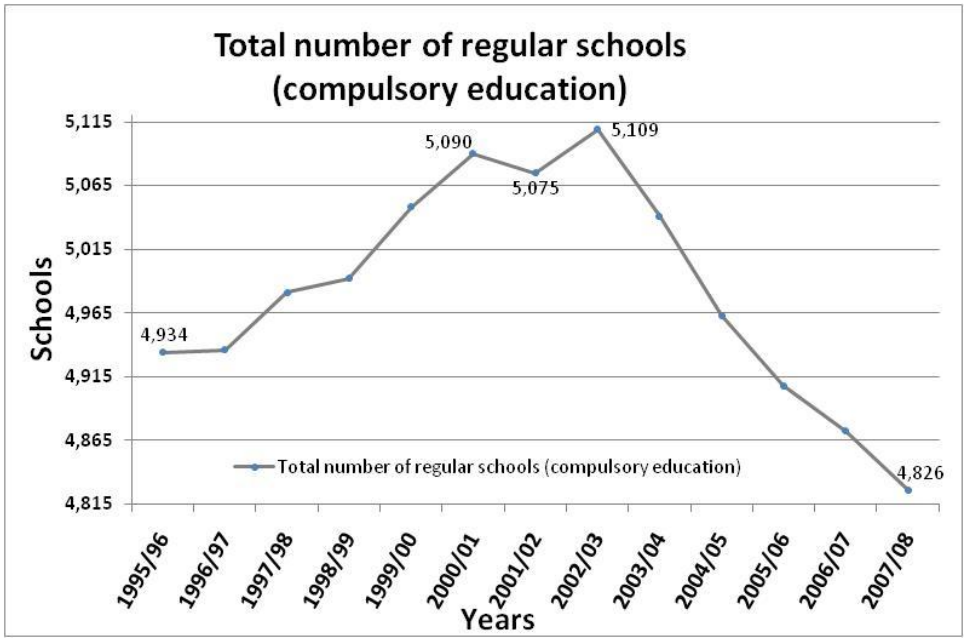
Figure 4.4
Student population at special schools, 1995-2008



** includes pupil with impaired sight, deaf/with impaired hearing, with speech impairment, and with additional functional disabilities*

The trend in Figure 4.4 of the student population at special schools is proportional to the trend of the student population at regular schools as demonstrated in Figure 4.3.

Figure 4.5
Total number of regular schools (compulsory education), 1995-2009

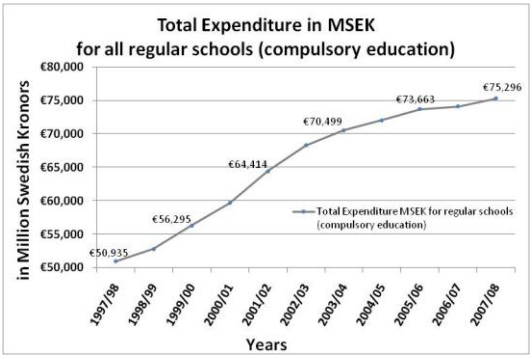


**includes municipal schools, sami schools, independent schools, international schools, and national boarding schools*

The trend is also similar to Figure 4.5, showing the total number of regular schools in Sweden. Once the student population increases its enrollment then there will be a need for more schools to adjust to this growth in population. It will be interesting to explore whether the special schools will increase in enrollment is parallel to the regular schools. Also, will the enrollment of deaf students be slightly unchanged because of cochlear implants? In the 2007-08 academic year, 4,826 regular schools were operating in Sweden. Further details on these statistics can be found in Appendix F.

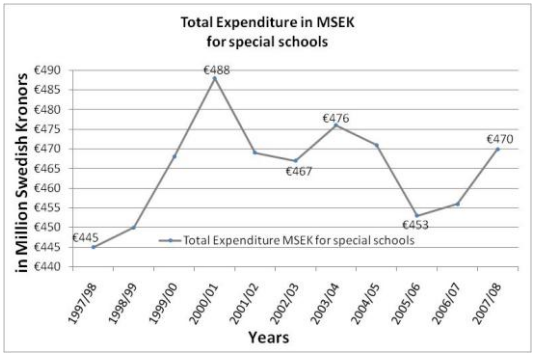
Government spending on education

Figure 4.6
Total expenditure in MSEK for all regular schools (compulsory education), 1997-2008



**includes municipal schools, sami schools, independent schools, international schools, and national boarding schools*

Figure 4.7
Total expenditure in MSEK for all special schools, 1997-2008



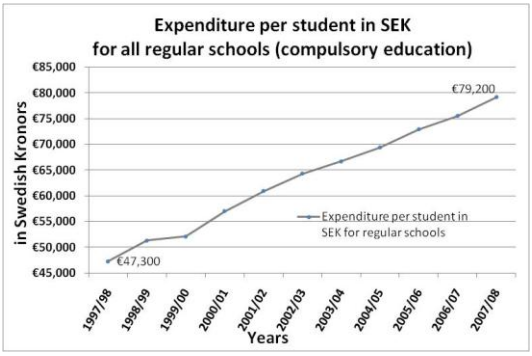
**covers Manilaskolan, Ostervangsskolan, Vanerskolan, Birgittaskolan, Kristinaskolan,Asbackaskolan, Hallsbaoskolan. and Ekeskolan*

Figure 4.6 demonstrates that government increases spending every year to regular schools; on the other hand, Figure 4.7 shows that government spending varies each year among special schools. Special schools went through some administrative changes over the years but this does not explain the reasons for cuts and increases in spending. The researcher was unable to explain these changes from the English sources, available only every three years. It is possible that having fewer students brings less government funding to support special schools.

Government spending toward regular schools and special schools is different. The currency for Sweden is in Swedish Kronors or SEK. In the 2007/08 fiscal years, expenditure for regular schools was about 75.3 billion SEK (approximately $10.9 billion) and about 470 million SEK (approximately $68 million) for special schools. Expenditures for regular schools covers tuition, premises, school meals, teaching materials, equipment, library, school transportation, student welfare, and other. The top four expenditures for regular schools were toward tuition (51%), premises (19%), other (11%), and school meals (6%). Expenditures for special schools have similar list to regular schools except

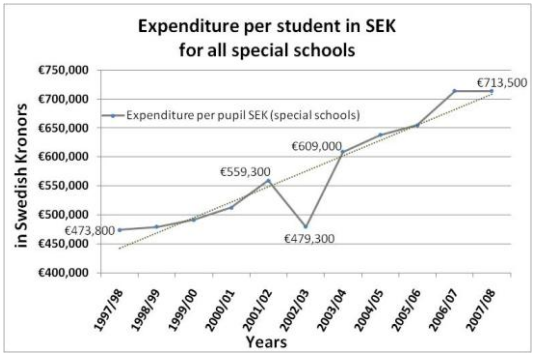
'tuition' was replaced with 'teaching' and 'student accommodation' (dormitory) was added. The top four expenditures in special schools was toward teaching (35%), other (22%), premises (16%), and student accommodation (13%).

Figure 4.8
Expenditure per student in SEK for all regular schools (compulsory education), 1997-2008



**covers tuition, premises, school meals, teaching material, equipment, library, school transport, pupil welfare. and other*

Figure 4.9
Expenditure per student in SEK for all special schools, 1997-2008



**covers teaching, premises, school meals, teaching materials/equipment, school library, student accommodation, school transport/travel grants, pupil welfare, and other*

The expenditure in the 2007/08 fiscal year per student was 79,200 SEK (about $11,450) for regular schools and 787,700 SEK (about $113,900) for special schools (from Figures 4.8 and 4.9). Expenditure per deaf student attending a special school cost the government more than students attending any of the regular schools. For regular schools, it is unknown if their expenditure includes 'special accommodation' such as personal assistants or special departments to meet the needs of deaf students. Cochlear implants in children might reduce some of the expenses if they could integrate into regular schools without the help of special accommodations in the classroom such as personal assistants or interpreters. Although, Sweden promotes integration of a person with disabilities with the rest of society, it raises the question if the cost is a motivator for integration of deaf children with cochlear implant.

Statistics from Barnplantorna

Barnplantorna is part of the European Association of Cochlear Implant Users (Euro-CIU) and does bi-annual reporting of statistics for the number of cochlear implant users in Sweden. Not all data were available in the reports. Specific data was retrieved from 2002 to 2005 in the Annual European Inquiry of the Euro-CIU, the only set of data available to the public at this time. Data from 2006 to 2009 was data found in Barnplantorna's publications. Barnplantorna became more specific in its 2009 annual report, which defines the brands and the number of cochlear implants each child has (one or two). See Table 1 for findings on the number of cochlear implant users in Sweden.

Table 1. Number of cochlear implant users in Sweden, 2002 to 2009

Number of CI Users	2002	2003	2004	2005	2006	2007	2008	2009
Total CIs reported	730	810	1100	1160	n/a	n/a	n/a	n/a
By Adults	500	500	700	n/a	n/a	n/a	n/a	n/a
By Children	230	310	410	n/a	480	n/a	530	569

**Data retrieved from Barnplantorna and Euro-CIU, see sources in Appendix G*

Although there was some data not available, a growth in the number of children using cochlear implants was noticed. It does not indicate whether the child received a cochlear implant soon after the Universal Neonatal Hearing Screening process, or the age when the child received a cochlear implant. The test was used to identify all the infants regardless of age at implantation. Barnplantorna mentioned in its *Hearing Aids and Baha* section of the website that, in 2008, there were approximately 10,000 deaf children aged up to 20 years. Also, it was noted that 200 children are born each year and are in need of hearing aids or cochlear implants (Barnplantorna, 2009b). In a publication *Cross-cultural definition of inclusino for deaf students: a comparative analysis* by Deafness and

Education International, it was mentioned that approximately 80 percent of the children received cochlear implants at early age (Foster, et al., 2003).

Conclusions of Statistics:

While there are no national statistics on the deaf population, there has been some data scattered among the various organizations and agencies. There were some statistics found through Skolverket, Statistics Sweden Agency, Euro-CIU, Barnplantorna, SDR, and HRF. Skolverket and Statistics Sweden Agency both share similar data on the student population in Sweden. Skolverket published specific statistics on the student population in compulsory education including special schools. It was shown that the student population for both regular schools and special schools has declined in the recent years as well as the number of schools. The researcher analyzed a set of data, *Population and Population Changes 1749-2008,* from the Statistics Sweden Agency and it showed that the overall population gradually increased exponentially but the birth rate rose and fell over a series of decades. Death rates appeared to be stabilizing in the past few years. It is predicted that the student population will increase after 2009 along with the number of schools to meet the capacity of these students. Expenditures for regular schools continue to increase except for special schools where there has been some restructuring. It is expected that spending for special schools will stabilize since all eight special schools were centralized under the National Agency for Special Needs Education and Schools. The information on children with cochlear implants in regular schools is not available to determine if these children are integrating.

There were several questions mentioned at the beginning of the paper and it will be answered here. *Are there any statistics on the number of deaf people wearing hearing aids or cochlear implants?* Yes, there are some statistics provided by Barnplantorna but they do not specify the number of deaf children in regular schools or special schools. Also, there are no statistics for the number of hearing aids users. It is wondered if any of these children continue to use Swedish Sign Language after receiving a cochlear implant. This could be explored in future research. *How many deaf children with cochlear implants are integrated in compulsory schools and special schools?* Unfortunately, this statistic is not available and the only data provided are the number of students in special schools by Skolverket and the Statistics Sweden Agency. Barnplantorna is the only organizations that reports details on how many cochlear implant users are in Sweden.

5.0 Comparison of Sweden and the United States with several implications for policy makers

There are no laws that narrowly focus on the deaf population in either Sweden or the United States. In Sweden, there is no limitation to the use of cochlear implants other than manufacturer's recommendations and the cochlear implant hospital's experience. In the United States, the Food and Drug Administration has to approve certain cochlear implant models before they can be distributed throughout the country. There are multiple laws that address hearing loss as a disability and concentrate on some of the issues regarding people with disabilities such as employment, health care, education, public accommodations, and the use of verbal and nonverbal communications. This section will

compare Sweden and the United States stand on communications, disability policies and political process, education, health care, and the impact of cochlear implant technology.

Communications

The Swedish government recognized Swedish Sign Language as an official language for the deaf. Sign language courses are offered at universities, and teachers are required to master this language when teaching deaf students, and interpreters are required to have university level education in Sign Language before they are allowed to interpret for the deaf. Bilingualism is a policy and encouraged for deaf people in Sweden. Children are taught a foreign language in schools so that they can participate in the international community. To safeguard the Swedish language, the Language Act (2008/09:153) went into force on July 1, 2009 to declare Swedish as the main language in Sweden. Even though it was acknowledged in 1981 by the Swedish Parliament that Swedish Sign Language is the natural language for the deaf people, it was mentioned again in the Language Act to protect and develop it. Sweden is diverse with various foreign languages and immigrants from other countries. Everyone who works or resides in Sweden has the right to learn in his or her native language, however, most use Swedish as their main form of communication. The Language Act emphasizes the Swedish language as the primary language for international contexts and public services but organizations and government agencies still have the option to provide some information in English. The Language Act also protects the national minority languages such as Finnish, Yiddish, Sami, and Swedish Sign Language. The deaf children can be taught Swedish Sign Language as their natural language and then spoken Swedish after they

have mastered written Swedish. To participate in the international community, deaf children would have to learn a third language such as English or German just like other students in regular schools. The deaf people would not just be bilingual but multilingual if they mastered a third language after Swedish Sign Language and Swedish. With resources available, the publications and documents would be translated into another language allowing the international community to learn more about Sweden. In addition, there are organizations that advocate the use of Swedish Sign Language or the use of assistive hearing devices such as cochlear implants to encourage speech development but never have both in their mission statement to promote bilingualism. These organizations should consider incorporating bilingualism into mission statement.

In the United States, American Sign Language is acknowledged as a language commonly used in the deaf community but is not formally recognized as an official language as there are other communication methods such as Signed Exact English (SEE), Pidgin Signed English (PSE), Rochester Method (finger spelling), oral method, cued speech, to name a few that are used within the deaf community. According to the Americans with Disabilities Act (ADA), interpreters must be qualified to interpret for the deaf. The statement of "qualified interpreters" in the ADA left no established standard for best quality interpreting for the deaf community. Some interpreters received a certification through Registry of Interpreters for the Deaf (RID) while others received university level education. Currently there are no mandates for teachers of the deaf, who are not required to be fluent in sign language in most schools with deaf students. The United States is a predominately English speaking country with many minority languages

such as French and Spanish but most of the publications are printed in English as expected that everyone should know how to read and write in English.

Sweden and the United States both have different communication environments. Sweden promotes bilingualism policy within their community with Swedish as a primary language but in the deaf community, Swedish Sign Language is their official language. It would be a utopian society if everyone in Sweden knew sign language because it would eliminate the challenges deaf people face everyday but in reality this will not happen. As for the United States, it would be recommended that a standard for a sign language skill be established for teachers and interpreters to ensure quality communication for the deaf in the Americans with Disabilities Act. The words "qualified interpreters" in the Americans with Disabilities Act, offered a variation of poor to wonderful translation of the spoken English language to American Sign Language. The United States government should recognize American Sign Language as an official language so that schools can consider American Sign Language as a subject for others to learn and communicate with the deaf community. There are some schools that offer American Sign Language as a course in their curriculum but many schools do not because it is not considered a formal language like French or Spanish.

Disability policy and political process

Sweden concentrates its disability policy on 1) identifying and removing obstacles to full participation and full equality in society, 2) preventing and fighting discrimination, and 3) promoting equality between disabled girls and boys, women and men" (Swedish Institute, 2010). Many Swedish politicians pass all-inclusive legislations or discuss

societal issues that affect everyone making Swedish society accessible to all. Currently, the Handisam (The Swedish Agency for Disability Policy Coordination) is working to accelerate and coordinate the benefits of this disability policy through new objectives such as "Design for All," more government accessibility, and continuing to combat discrimination in schools. In the literature review, there were no mentions of lobbying from organizations or to politicians toward the legislative process in Sweden. The Swedish people consider lobbying dishonorable and do not consider it very democratic (Kiros, 2007). The Swedish people carry out a consensus attitude by working with their government through different ministries and departments. The Equality Ombudsman investigates each complaint and attempts to resolve the issues filed by the citizens.

The United States has the Americans with Disabilities Act (ADA), which concentrates on some of the societal issues such as employment, health care, education, communications, and public accommodations that people with disabilities are challenged with on a regular basis. The United States also have the Individual with Disabilities Education Act (IDEA) and the Rehabilitation Act that focus on education and discrimination.

Advocacy organizations in the United States take an aggressive approach to lobby government for changes in disability policy because there are still many barriers to fix. For example, information in the media is not entirely accessible to the deaf population. There are some videos on the Internet that are not captioned or interpreted. The government is working to include new technology in their legislation when it affects the deaf population. Corporations or special interest groups have also used lobbyists to make changes in policies. In the federal court, lawsuits are used to challenge certain policies

with the support of the Constitution and state laws. Lobbying and lawsuits are confrontational types of strategies used by the people to get specific policies changed. An example of a confrontational attitude toward the use of cochlear implant is a current situation in Spokane, Washington. A deaf child disliked wearing cochlear implants and was forced to wear them through a court order by her hearing mother, a divorced parent who wanted to encourage spoken communication. The deaf father was flexible enough to allow his daughter to make her own decision to wear it or not. The daughter wanted to be like her father and was comfortable with using only sign language. There is no bilingual policy to protect the deaf child's right to communicate in the language that he/she preferred. The community of deaf and hard of hearing people has reacted against the court order through YouTube and blogs. This case is considered an act of child abuse on behalf of the mother (Boggs, 2010).

Sweden and the United States both have different disability policies and attitudes to convince the government to change the policies. Sweden has a consensus and democratic attitude while the United States has a lobbying and confrontational attitude. Sweden must consider disabled citizens in every policy-making process while disabled citizens must lobby or fight for their rights in the United States. Sweden established the Handisam in 2006 to explore and improve the benefits of its disability policy for Swedish citizens. The United States should set up an ad-hoc committee similar to Sweden's to review the Americans with Disabilities Act to improve many of the flaws that left out many disabled Americans. With this committee, there should be developed guidelines for employers and corporations to make media accessible for all and government should find ways to provide funds for small businesses that are unable to financially cover the cost of

access services for the deaf community. Sweden strives to be a model for cochlear implants and also an advocate for disabled citizens.

Education

Education in Sweden allows deaf students to attend any of the regular schools with accommodations provided such as personal assistants. There are special schools with additional supports for deaf students. Teachers of the deaf at special schools are required to be fluent in sign language and are offered sign language courses at universities or at the school they teach during their free time.

Deaf students in the United States can attend either public or private schools with accommodations if requested. Often parents or the deaf student do not know that it is required by law for schools receiving federal funding to provide accommodations. The teachers of the deaf are not required to be fluent in sign language, but interpreters may be available upon request. The word "qualified interpreters" in the Americans with Disability Act left a broad definition of its meaning and brought conflicting expectations between consumers and the access services such as Video Relay Services (VRS) or interpreting agencies. There is no specific level of standard for interpreting skills required to meet the needs of deaf people by the federal government. The Registry of Interpreters for the Deaf (RID) is an organization for professional interpreters and they develop and maintain high standards for its members to be certified and ensure a high quality of interpreting for the deaf (Registry of Interpreters for the Deaf, 2007). However, the federal government does not mandate this standard for all community sign language

interpreters. Many community interpreters are skilled in American Sign Language, but only a few are certified.

Education is accessible to the deaf population in Sweden and the United States. However, the United States needs to improve in educating the parents, students, and the school on accessibility issues such as providing interpreters or have more teachers skilled in sign language available for the deaf.

Health care

It is mandatory to have Universal Neonatal Hearing Screening in Swedish hospitals because proper health care is essential for every newborn especially those with a hearing loss. Parents will be referred to a medical team specialized in deafness and offered medical treatment such as a cochlear implant, middle-ear implant, or hearing aid for their deaf child at no cost to the family other than that coming from national taxes. This mandate is a wonderful way to encourage early intervention and helps the newborn develop socially, psychologically, and emotionally with their parents and peers.

Universal Neonatal Hearing Screening is required by 30 states that passed it as mandatory in the United States while it is optional in the other 20 states (National Conference of State Legislatures, 2010). Once the newborn is delivered, there is a quick health check up and the baby is sent home with the parents. Sometimes early intervention is lost with parents who were not informed that their child is deaf unless they ask or the hospital decided not to administer the Universal Neonatal Hearing Screening because of constraints (National Institute on Deafness and Other Communication Disorders, 2003). Hearing assistive devices are covered as out-of-pocket expenses, through insurance

companies, or government agencies. An assembly bill (AB 2072) in California, regarding the hearing screening process, is being challenged by the public for a simple change of language. The new change to the current bill will require an audiologist to provide written and electronic information about communication options to the parents within the first three months of the newborn's life (Official California Legislative Information, 2010). It may sound like a clearly positive change of language in the policy, but opponents of this amendment disagreed and stated "this bill is flawed because it is biased toward one communication option, listening and speaking" (California Association of the Deaf, 2010). The struggle for preserving the use of American Sign Language can be recognized in people's complaints in blogs and youtube videos against this amendment on the AB 2072 assembly bill. If the United States had a bilingual policy similar to Sweden's then concern for the use of both sign language and spoken communication would help future policies be neutral and inclusive.

Health care costs in Sweden and the United States are very different. The health care in Sweden is heavily covered through taxes while private insurance companies and out-of- pocket expenditures from taxpayers covers the United States' health care. The United States has changed health care through a reform to improve benefits and access for Americans without insurance and remove the barriers that many insurance companies have preventing Americans from getting the care they need (U.S. Department of Health & Human Services, 2010.) The United States government should make Universal Neonatal Hearing Screening a federal law for all hospitals to provide early intervention and refer parents to proper care if the newborn is found with a hearing loss.

In summary, Sweden's inclusiveness and disability policy is a model widely studied by other countries. The United States should borrow ideas that are working well in Sweden so that deaf Americans can benefit from it. Such benefits involve all-inclusive access to media and communications, access to government, removing barriers and discrimination, provide accommodations and awareness for deaf students and parents, and improving early intervention in *all* hospitals with mandatory Universal Neonatal Hearing Screening recommended.

6.0 Recommendations for future studies in Sweden

Communication

In Sweden, bilingualism of both Swedish Sign Language and spoken Swedish is a policy for the deaf community. It would be interesting to explore how prevalent is bilingualism among Swedish children with cochlear implants. Do deaf children with cochlear implants continue using Swedish Sign Language? Do the parents continue to communicate in Swedish Sign Language after their deaf child has mastered the spoken language with cochlear implants?

Education

Since statistics are available for special schools, further study could explore how many deaf students have cochlear implants or hearing aids in regular schools. Also, what kinds of accommodations do deaf students in regular schools use? What information are these deaf students missing in the classroom? What are the classroom placement settings for deaf students, hard of hearing students, and regular students? In statistics of

enrollment of deaf children in special schools, it would be interesting to see if cochlear implants have any influence on enrollment for regular schools or specials schools. Will the enrollment remain the same or different for both regular and special schools for children using cochlear implants? In addition, it is unknown if expenditures for regular schools include special accommodations such as personal assistants or special departments for the deaf. Does the cost of integrating deaf students into regular schools instead of special schools the reason why government is supporting bilingualism?

Health care

Parents are informed whether their child is deaf or not upon the Universal Neonatal Hearing Screening by a doctor. Suppose the parents had the opportunity to meet a deaf representative to discuss deaf culture and identity, how will that affect their choice of selecting the right hearing assistive device? How much information does the doctor relay about bilingualism?

Organizations and community perspectives

It would be interesting to further explore organizations and their attitude toward cochlear implant technology. Are some deaf people in Sweden resisting cochlear implants out of fear of losing their deaf culture or are they embracing it because they are closer to being a hearing? How does a deaf organization's attitude toward cochlear implant influence cultural identity?

7.0 Researcher's closing summary

The main research topic, *the emergence of cochlear implant technology impacting Sweden's environment toward existing disability policies and procedures in education, health care, and organizations serving deaf people,* has been a fascinating area of study which involved analyzing Sweden as a model of its bilingual policy, studying attitudes of people towards cochlear implant technology, and revealing the actual practice of people following the disability policy. It was appreciated with high regard knowing that Sweden encourages accessibility for all and integrating disabled citizens with the rest of society. Existing disability policies are still being worked on through the Handisam, an equal access committee established by the government. Handisam continues to explore and increase the benefits of its policies for people with disabilities by creating guidelines and better access. The emergence of cochlear implants technology has created a ripple in a pond among the deaf community. Deaf people value government's recognition of a bilingual policy in protecting their right to use both Swedish Sign Language and spoken Swedish. There are some people that are embracing cochlear implant technology and some resisting it. In Sweden, cochlear implant technology has made an impact on perspectives in education, health care, government, and the identity of cochlear implant users in the deaf community.

In 2007, Swedish educational statistics were showing a decline of enrollment in all compulsory schools partially because of a stable death rate and low birth rate. Eventually when the birth rate increases, the enrollment in schools will gradually increase. There were no statistics available to demonstrate how many deaf students or cochlear implant users are in regular schools. There were statistics for the number of deaf

students in special schools but no details on how many have hearing aids or cochlear implants. The Swedish National Agency for Education could conduct a nation-wide survey for a demographic data of deaf students in compulsory education. It is possible that over time, the cochlear implant users will integrate into regular schools instead of special schools, but regular schools do not have the interactive bilingual environment that special schools do. With cochlear implant users integrating into regular schools, the bilingual policy may need to adjust and enforce communication of both Swedish Sign Language and spoken Swedish in the regular classroom.

In health care, the main goal for many medical experts is to find a cure for many diseases or make a person's physical well being normal possible. For a deaf person, any hearing assistive devices are designed to meet that objective. The bilingual policy of both Swedish Sign Language and spoken Swedish does not satisfy the medical perspective to restore normal hearing, but technologies or surgeries are becoming better at accomplishing this goal. Medical experts will continue to research and find better technology or develop stem cells to replace the dysfunctional parts of the ear. It is with no doubts that cochlear implants would be most favored and recommended over other type of hearing devices by these medical experts.

The objective of the Swedish government for all of its citizens is to integrate and make many of them independent and active participants in society. The government works with minority groups to make sure that the legislative process is inclusive and the policies provide equal access for all. The government has already recognized Swedish Sign Language for deaf people and promotes a bilingual policy. In 1995, cochlear implant technology began to emerge among deaf children in Sweden. Culturally, the

Swedish people consider having negative reactions impolite and undemocratic. Through the literature review, tension between different organizations that supported either sign language or spoken communication was noticed. However, the researcher never found one organization that supported the bilingual policy in its mission statement. Cochlear implants would be embraced if the technology supported bilingual communication or rejected if the technology chose one communication method over bilingual communication. The researcher predicts that cochlear implant technology will change the future of deaf people. Once the deaf children with cochlear implants become adults, they will use less sign language and more oral communication.

There were mixed reactions toward cochlear implants in deaf children in the Swedish community. Of the organizations presented in this paper, Barnplantorna and Sveriges Dövas Riksförbund (SDR) both have different objectives. Both organizations support bilingualism through different sources, but do not incorporate Swedish Sign Language or spoken Swedish together in its mission statement. Barnplantorna's mission statement continues to support any hearing assistive technology to help a deaf person hear and develop spoken language while SDR's mission statement supports the value of Swedish Sign Language. It was noticed through reading reports and observations by respondents to the questionnaire that SDR was struggling to preserve Swedish Sign Language despite the impact of cochlear implants among deaf children. SDR expressed this struggle in one of its annual reports, stating that they are not against cochlear implants but still support Swedish Sign Language as part of the identity of a cochlear implant user. The researcher has identified the emergence of "cochlear implant identity" among the cochlear implant users, who wanted to belong to a group with similar

experiences but were lost in the tension of the two different groups supporting one or the other communication method in bilingualism. Barnplantorna is providing support to deaf children with cochlear implants. If SDR does not find a way to embrace these cochlear implant users into its membership then deaf children with cochlear implants will grow to see no need to participate in events with SDR in the future.

Concluding the researcher's comments on the impact of cochlear implants toward different perspectives in Sweden, there are possibilities that cochlear implant technology will become more sophisticated through stem cells and renewable energy research. It was brought up in a discussion that in theory, cochlear implants may be advanced further to be implanted alone in the ear without an external component and this will be powered by a human battery. A human battery is a thermoelectric generator that draws electrical energy from a change of body temperature (Sherer, 2007). Scientists are experimenting with this thermoelectric technology and once developed, it will change the aesthetic of cochlear implant technology in the future. New cochlear implant users will be able to blend in with society with this, not yet developed, hidden technology. The other possibility that will impact the development of cochlear implant technology is stem cell research. Through stem cell research, scientists can genetically cultivate new cell tissues that could replace the damage cells in the ear (Coghlan, 2009). If successful with this approach, the future of deaf identity and deaf culture will diminish when children with a hearing loss are identified immediately through hospitals' early intervention and "cured" with stem cells surgery.

8.0 References

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9.0 Appendices

Organization Questionnaire Packet

Appendix A: Cover letter from committee chair
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Other Sources

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Appendix A: Cover letter from committee chair

R·I·T

Rochester Institute of Technology

department removed
52 Lomb Memorial Drive
Rochester, New York

14623-5604

phone number removed
email removed

March 28, 2008

[name of organization]
[name of contact person]
[email of contact person]

Dear [name of contact person]:

I am writing to you on behalf of a graduate student, Christopher Samp, who is enrolled in the Public Policy Program at Rochester Institute of Technology. Christopher is doing his thesis research on *Current Circumstances of Cochlear Implants Users among the Deaf Youth in Sweden's Educational System*. He has developed a set of questionnaires to collect information regarding procedures for obtaining: cochlear implant and policy statements from various advocacy organizations; statistical data from the government regarding demographics of deaf students in compulsory schools; and trends regarding hearing assistive devices in Sweden. If you are able to help or know someone who would be willing to answer his questionnaires, Christopher would appreciate all the support and information you can provide. He needs the questionnaire completed as soon as possible so that he has time to analyze the data during May prior to graduation.

If you have any questions about this research, feel free to contact Christopher Samp at ***email removed*** or to myself at ***email removed*** or ***phone number removed***.

Sincerely,

James J. DeCaro, Ph.D.
Director, PEN-International
Thesis Committee Chairperson

Appendix B: Cover letter from researcher

March 28, 2008

[name of organization]
[name of contact person]
[email of contact person]

Dear [name of contact person]:

I am a graduate student in the Science, Technology and Public Policy program at Rochester Institute of Technology in Rochester, New York, United States of America. I am conducting my thesis research on *Current Circumstances of Cochlear Implants Users among the Deaf Youth in Sweden's Educational System*.

I would like to ask for permission from you or a representative for this research. It would be helpful if you could complete the brief questionnaires as attached. Completion of the questionnaires is voluntary. It may take about 1 to 2 hours of your time. You can choose not to participate and withdraw at anytime without complications. Your participation will help me gain insight on current circumstances of cochlear implants in the deaf community of Sweden. If you would like to take part in this project please read the informed consent section before completing a questionnaire.

If you have any questions about this research, feel free to contact me at ***email removed*** or to my thesis committee chairperson, Dr. James DeCaro at ***email removed*** or ***phone number removed***.

Sincerely,

Christopher Samp
Researcher, Graduate Student at Rochester Institute of Technology

Thesis Committee Members:

Dr. James DeCaro	(Committee Chairperson)
Dr. Catherine Clark	(Committee member)
Ms. Patricia Mudgett-DeCaro	(Committee member)
Dr. Franz Foltz	(Graduate Coordinator)
Dr. James Winebrake	(Chair of Public Policy Department)

Appendix C: Consent form

Consent Form

Researcher: Christopher Samp, *BS/MS Public Policy, Rochester Institute of Technology*
Email: ***email removed***
Project Title: Current Circumstances of Cochlear Implants Users among the Deaf Youth in Sweden's Educational System

The information that Christopher Samp will receive from this research is shared between the researcher and the thesis committee members. Taking part of this research is voluntary, and no one will hold it against you if you decide not to do it. If you do take part, you may stop at any time without penalty. You may ask Christopher Samp to withdraw the data when the research has been conducted. Once the research is done, your name and all communication will be eliminated unless Christopher is given consent to refer to you and cite his sources.

By responding to the researcher with the email that you use, you verified that the email address is in true ownership to you and is not used by someone else.

Giving permission:

Please indicate that you understand and agree to participate by stating 'yes' or 'no' to each of the questions below:

•I would like to give consent for my input in this research; I know what I will have to do and that I can stop at anytime:
☐ *Yes* or ☐ *No*

•I would like to give permission to the researcher to cite my name in any publications:
☐ *Yes* or ☐ *No*

If you state 'no', Christopher will make sure that he will do everything to protect your privacy. Your identity will not be revealed in any publications that might result from this study. This includes your contact information.

•May the researcher contact you further for questions or clarifications?
☐ *Yes* or ☐ *No*

Name:	
Position:	
Mailing Address:	
Email Address:	
Phone Number:	

This contact information that you will provide will not be shared with anyone other than Christopher Samp and the thesis committee members.

Not Participating:

If you chose not to participate in this research, it is helpful to know the reason why. Please explain briefly back to the researcher, and this response is optional.

Appendix D: Organization Questionnaire 1 & 2

Organization
Questionnaire (Part 1)

1. What standard procedure did the patient go through for a check up of hearing loss?

2. What was the patient or the parents informed of the hearing loss?

3. Where did the patient go when a hearing loss was discovered?

4. Who was introduced to the patient from the medical team that is receiving a hearing device?

5. What suggestions were given to the patient on the types of hearing devices available?

6. What hearing devices did the patient or parents pick and why?

7. What procedures did the person go through in receiving a cochlear implant?

8. After the patient received a cochlear implant, what training did the patient go through?

9. What was the experience of the parents in Swedish Sign Language? How much was learned?

10. What roles did the patients experience with the hospital and the Swedish National Association of the Deaf have in the cochlear implant process?

Policy Statement
Questionnaire (Part 2)

1. Organization's mission statement:

2. Tell me about the organization's role in the cochlear implant process. How does the organization influence the cochlear implant process?

3. What is the policy statement of the organization toward cochlear implant?

4. What is the policy statement of the organization toward hearing aids?

5. What is the position statement of the organization toward Swedish Sign Language?

6. How many members are in the organization?

Appendix E: Hospital Questionnaire

Hospital Questionnaire

1. What is the standard procedure for a check up of a patient's hearing loss?

2. How is the patient or the parents informed of the hearing loss?

3. What referral was made to a patient when hearing loss was discovered?

4. Who is on the medical team that was introduced to the patient receiving a hearing device?

5. What suggestions are made to the patient on the types of hearing devices?

6. Which hearing devices would be recommended and why?

7. What is the standard procedure for a person to receive a cochlear implant?

8. After the patient receives a cochlear implant, what training is recommended?

9. How are the parents of the patient informed about Swedish Sign Language?

10. What roles did the parents and the Swedish National Association of the Deaf have in the cochlear implant process?

Appendix F: Data Statistics Sources

For Table 1, Figure 1-7 (page 97-103):

Statistiska centralbyrån
6 Specialskolan *(in Swedish)*
6.1 Elever i specialskolan läsåren 1998/99 – 2006/07.
http://www.scb.se/statistik/_publikationer/UF0524_2007A01_BR_07_UF0107TAB.pdf

Skolverket (report no. 192)
Descriptive data on child care and schools in Sweden in 2000 *(in English)*
Table 16. The number of pupils in compulsory school on 15 October 1995-1999 by principal organizer (page 27)
Table 17. Number of municipalities, school management areas, schools and pupils in compulsory school, 15 October 1995-1999 (page 27)
Table 25. Expenditure for the compulsory school in 1997, 1998 and 1999, by principal organizer and type of expenditure (current prices) (page 35)
Table 28. Number of pupils at special school, 15 October 1995-1999 (page 38)
Table 31. Expenditure for special school in 1997, 1998, 1999 (current prices) (page 41)
http://www.skolverket.se/publikationer?id=815

Skolverket (report no. 236)
Descriptive data on childcare, schools and adult education in Sweden 2003 *(in English)*
Table 16. The number of pupils in compulsory school on 15 October 1998-2002 by principal organizer (page 34)
Table 17. Number of municipalities, school management areas, schools and pupils in compulsory school, 15 October 1998-2002 (page 35)
Table 25. Expenditure for the compulsory school in 2000, 2001 and 2002, by principal organizer and type of expenditure (current prices) (page 46)
Table 31. Expenditure for special school in 2000, 2001 and 2002 (current prices) (page 53)
http://www.skolverket.se/publikationer?id=1269

Skolverket (report no. 283)
Descriptive data on pre-school activities, school-age childcare, schools and adult education in Sweden 2006 *(in English)*
Table 17. The number of pupils in compulsory school on 15 October 2001-2005 by principal organizer (page 38)
Table 18. Number of municipalities, school management areas, schools and pupils in compulsory school, 15 October 2001-2005 (page 39)
Table 26. Expenditure for the compulsory school 2001-2005, by principal organizer and type of expenditure (current prices) (page 50)
Table 30. Number of pupils at special school, 15 October 2001-2005 (page58)
Table 33. Expenditure on special school 2001-2005 (current prices) (page 61)
http://www.skolverket.se/publikationer?id=1705

Skolverket (report no. 320)
Descriptive data on pre-school, childcare, school and adult education in Sweden 2008 *(in Swedish)*

Table 16. The number of pupils in compulsory schools on 15 October 2003-2007 by principal organizer (page 29)
Table 17. Number of municipalities, school managements area, schools and pupils in compulsory school, October 15 2003-2007 (page 30)
Table 28. Expenditure for the compulsory school 2003-2007, by principal organizer and type of expenditure (current prices) (page 43)
Table 33. Number of pupils in special schools October 15 2003-2007 (page 50)
Table 36. Expenditure on special school 2003-2007 (current prices) (page 52)

http://www.skolverket.se/publikationer?id=2115

Appendix G: Swedish Policies dealing with people with disabilities

The Sweden's Government Bill of 1981 (1980/81:100)

In 1981, Sweden recognized the bilingual approach within the deaf and hard of hearing community. This bill acknowledges the use of visual/gestural sign language among its members, and gave the community a voice of its own. This is a unique recognition of the language used by the deaf and hard of hearing Swedish people that no other countries have in their laws.

Health and Medical Service Act of 1982 (1982:763)

The Health and Medical Service Act is an essential need for all Swedish residents. The goal of this Act is to provide equal access to good health care. The cost of health and medical care amounts to SEK 223 billion (approximately $30.9 billion) or 8.4% of Sweden's GDP. This budget includes the cost of pharmaceutical products, dental care, eyeglasses and patient fees. There are three levels of government that handle different areas of responsibilities: state, county councils, and municipalities. The state is responsible for nationwide policies and medical care programs. For the Swedish deaf, the county councils work with the residents in their region toward services that require considerable resources such as interpreting services. There are 21 county councils that offer their residents services such as habilitation and rehabilitation, assistive devices for persons with functional impairment, and interpreting services.

The municipalities are local governments that work with their residents so they receive the help and support they need such as care of elderly and people with disabilities

living in special accommodations. The municipalities and county councils work together under a governing body known as the Swedish Association of Local Authorities and Region (SALAR). The services vary among the regions and through SALAR, the municipalities negotiate with the county councils for resources that are not within their budget. The local residents are not limited to the services provided by their own local government and are entitled to freedom of health care (2003) anywhere else in the country according to a provision in the Health and Medical Service Act. The Act allows residents to seek care on the same terms as in their own county council area (Regeringskansliet: Government Offices of Sweden, 2009).

Act concerning Support and Service for Persons with Certain Functional Impairments (1993:387)

This Act focuses on specific disabilities such as mental retardation and autism. The Act describes the role of personal assistants, where the municipalities provide the person with functional impairments assistance with his or her personal hygiene, meals, dressing and undressing, and communicating with others of their certain needs. The municipality is responsible for the cost of personal assistants.

The Assistance Benefit Act (1993: 389)

This Act refers to using public funds for the cost of personal assistants. The Swedish Social Insurance Agency makes the regulations and determines the benefits.

Social Services Act (2001:453)

The Social Services Act ensures that all people in Sweden receive economic and social security, equality of living conditions, and active participation in the life of the community. The municipality is responsible for making sure that the Act is enforced. Ultimately, certain individuals with disabilities will receive the assistance and support that they need to participate actively and equally as with any other citizens.

Appendix H: Swedish Version of Policy Statements

The objectives of Barnplantorna in Swedish:

*"**BARNPLANTORNAS ÄNDAMÅL***

- *Att tillvarata barn och ungdomars intressen i en kraftigt föränderlig värld utifrån fokus på varje individs möjligheter, utmaningar och visioner. Barn med olika hörhjälpmedel.*
- *Att arrangera träffar för social gemenskap för medlemmarna.*
- *Att bistå familjer med kontakt med andra familjer dvs skapa nätverk mellan medlemmarna för att föräldrar ska kunna ta en aktiv del i sitt barns utveckling till självförtroendefulla och självständiga individer.*
- *Att informera medlemmarna om CI och den tekniska utvecklingen inom cochleaimplantat området. Detta åstadkommes genom ett brett samarbete med tillverkare såväl nationellt som internationellt.*
- *Att samarbeta även med tillverkare av olika hjälpmedel till CI och hörapparater samt tillverkare av Baha och representanter för hörapparatindustrin.*
- *Att informera medlemmarna om möjligheter i olika förskole/skolval samt stödja den enskilda familjen i sitt beslut avseende förskole/skolval oberoende av valet.*
- *Att informera och sprida kunskap om våra barn till professionella inom habilitering/förskola/skola*
- *Att informera om det väsentliga i att barnens hörsel är viktig för språkutveckling (tal, skrift) och utvecklande av ett åldersadekvat ordförråd.*
- *Att bedriva ett brett intressepolitiskt arbete för att tillvarata medlemmarnas intressen vid kontakter med myndigheter, förskolor, skolor, enskilda professionella samt habilitering.*
- *Att följa forskningen inom döv/hörsel området genom kontakter med olika forskarnätverk både i Sverige men också globalt.*
- *Att informera den breda allmänheten om cochleaimplantat på barn (som ett relativt nytt hörhjälpmedel) för att tillse att alla barn med olika hörhjälpmedel – genom förståelse i samhället – erhåller optimala förutsättningar i det samhälle som vi alla vill vara en aktiv del av.*
- *Att bedriva en bred kursverksamhet för föräldrar såväl som yrkesverksamma inom habilitering, förskola och skola.*

The objectives of the Equality Ombudsman in Swedish:

Vad DO inte gör

DO:s uppgift är att motverka diskriminering på grund av kön, könsöverskridande identitet eller uttryck, etnisk tillhörighet, religion eller annan trosuppfattning, funktionshinder, sexuell läggning eller ålder. Men DO kan bara ingripa om det är frågor som rör arbetslivet, högskolor och universitet, skolan och skolbarnsomsorgen samt vissa andra samhällsområden. Skyddet mot diskriminering är också lite olika beroende på vilken diskrimineringsgrund det handlar om.

The objectives of SDR in Swedish:

"**SDR's vision**

- *I Sverige lever vi i ett samhälle där vi teckenspråkiga döva genom hela livet har rätt att uttrycka oss på vårt eget språk - teckenspråket.*
- *I detta samhälle kan vi döva kommunicera på teckenspråk och få kunskap och information på teckenspråk.*
- *Ingen ifrågasätter vår rätt och de politiska besluten som påverkar människor utesluter inte oss döva.*
- *Vi döva har full tillgänglighet till samhällets service, information, barnomsorg, utbildning, social omsorg, arbetsliv, kultur och föreningsliv. Den snabba IT-utvecklingen utesluter inte oss. Vi ingår som en självklar del i utvecklingen.*
- *Vi äldre döva har liksom alla andra äldre människor en fullgod äldreomsorg. För oss innebär det dessutom en fungerande teckenspråkig kommunikation.*
- *Vi döva lever i full delaktighet i samhällets olika nivåer, på våra egna villkor, med vårt eget språk - teckenspråk.*"

"***Barn behöver teckenspråk***

Barn med Cochlea Implantat behöver teckenspråk - också!

Det finns de som tror att dövrörelsen i Sverige är mot Cochlea Implantat (CI) och således mot att döva barn får hjälp med hörseln. Detta är fel. Vi är varken mot CI eller att döva barn får hjälp med hörseln. Tvärtom. CI är en avancerad hörapparat som fungerar bra för många döva barn. Men vi reagerar mot att läkare och andra framställer CI som ett tekniskt underverk som gör barnet hörande och därför inte behöver teckenspråk. ***Barnet blir inte hörande, utan snarare hörselskadat, och behöver teckenspråk för alla situationer i livet när hörseln trots CI inte räcker till.*** *Om och när CI tas bort är personen döv och beroende av kommunikation på teckenspråk. …*"

*Retrieved from SDR's website under "Children need sign language" (2009) and this also can be found in the SDR's 2007 annual report.